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CHILD HEALTH PROGRAMS AND PROPOSALS

HEARING

BEFORE THE

SUBCOMMITTEE ON HEALTH

OF THE

COMMITTEE ON FINANCE
UNITED STATES SENATE

ONE HUNDREDTH CONGRESS

FIRST SESSION

OCTOBER 2, 1987

Printed for the use of the Committee on Finance

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CHILD HEALTH PROGRAMS AND PROPOSALS

FRIDAY, OCTOBER 2, 1987

U.S. SENATE,
SUBCOMMITTEE ON HEALTH,
COMMITTEE ON FINANCE,
Washington, DC.

The Subcommittee met, pursuant to notice, at 10:05 a.m. in Room SD 215, Dirksen Senate Office Building, the Honorable George J. Mitchell, Chairman, presiding.

Present: Senators Mitchell, Bradley, Rockefeller, Chafee, and Durenberger.

[The press release announcing the hearing, the prepared written statements of Senators Bradley, Rockefeller, Heinz, and Durenburger and a background paper prepared by the Congressional Research Service follow:]

COMMITTEE ON FINANCE
United States Senate
205 Dirksen Building
Washington, D.C. 20510

PRESS RELEASE #H-61

FOR IMMEDIATE RELEASE
September 22, 1987

FINANCE SUBCOMMITTEE ON HEALTH TO HOLD HEARING ON CHILD HEALTH PROGRAMS AND PROPOSALS

Washington, D.C. -- Senator George J. Mitchell, (D., Maine), Chairman of the Subcommittee on Health, announced Tuesday that the Subcommittee will hold a hearing on child health programs and proposals that fall within the jurisdiction of the Finance Committee, including the Medicaid program and the Maternal and Child Health Block Grant program.

The hearing is scheduled for Friday, October 2, 1987 at 10:00 a.m. in Room SD-215 of the Dirksen Senate Office Building.

The Subcommittee will examine the current coverage and scope of services under these programs, as well as any deficiencies in child health programs that may need to be remedied. Mitchell stated that the Subcommittee is interested in hearing testimony on short-term initiatives that may be included in budget reconciliation legislation, as well as on long-term goals and initiatives.

Mitchell said specific areas of concern to the Subcommittee include initiatives to improve infant mortality and to provide catastrophic protection for children with extraordinary medical expenses.

OPENING STATEMENT OF SENATOR BILL BRADLEY

HEARING ON CHILD HEALTH PROGRAMS AND PROPOSALS

HEALTH SUBCOMMITTEEE OF THE SENATE FINANCE COMMITTEE

Mr. Chairman, I have made many statements, before this Committee and in other forums, about how I feel about the terrible tragedy of infant mortality. I said it is unthinkable that a child born in Trenton, New Jersey has less chance of surviving it's first year of life than a child born in Cuba; how shameful it is that we are allowing millions of women in this country to go through the entire nine months of their pregnancy without providing access to adequate prenatal care. But I will not be making a statement today.

What I will do instead is share with you three letters from among the more than 5,500 I have received from across the country--all 50 states, Puerto Rico and the Virgin Islands-- in support of action to lower our infant mortality rate. These three women have experienced first-hand the effect of being "not quite poor enough" to qualify for Medicaid, and not well-off enough to afford proper health care.

Listen to the words of these women as they describe the devastating effects of not being able to obtain health care for themselves, their unborn babies, and their children. It is through the simplicity and eloquence of their words that the crying shame of infant mortality can truly be captured.

A woman from Tennessee writes:

> "...You see, my husband and I recently ended a near-tragic ordeal much the same in your article. We were lucky, and I know God alone helped us and our precious baby son, Joshua. Because there was no help when we needed it, believe me!
>
> "We are not the typically thought of "welfare recipients." My husband as working when I found out I was pregnant, and I was seeking work, since we had just relocated to Tennessee from Texas. All of a sudden, I found myself pregnant and un-hirable, after having been the manager of an engineering design firm. Pre-natal care is expensive, and we could not afford it on my husband's wages alone -- $5.25/hour and no insurance!

"After calling endless state and local agencies seeking medical help, and being told we were 'over-qualified to meet the guidelines' (we were living on $742/month), I finally got to a doctor when I was 5 months along. My mother-in-law scraped together $120.00 for the initial doctor's visit and then $65.00 for another check-up.

"Two months later, my son was born prematurely at 7 1/2 months gestation period. He weighed 3 lbs. 4 ozs. and was transferred to the East Tennessee Children's Hospital to the Neonatal Intensive Care Unit where he remained for 5 long weeks. Thank God the hospital takes babies and children no matter their parents' ability to pay the debts incurred.

"God blessed us greatly, for we were able to bring our little "miracle" home in time for Christmas, 1986. He remained attached to a heart and apnea (breathing) monitor til July 26, 1987. "After Joshua was born, we finally received Medicaid to pay the almost $30,000 in medical expenses.

"For anyone doubting the need for such care, I suggest they take a few moments to visit a local Neonatal Intensive Care Unit. In my wildest dreams, I would never have thought my baby would be in that situation. After all, I have worked since I was 16 years old and never asked for help from anyone!

"I will never understand how so-called, well-education, intelligent government officials in Washington can't get it though their heads! It is so much more inexpensive to help pregnant women receive proper prenatal care than it is to wait until the damage is done! When will other Senators and lawmakers wake up and use their God-given common sense?"

A woman from Florida writes:

"...I am now very fortunate to be four months pregnant. However, the problems I am encountering are my worst nightmare. We are considered over the poverty level, my husband earns $850.00 monthly and works very hard to make ends meet. We pay $475.00

monthly for rent, almost $200.00 monthly for utilities and pay car insurance, groceries, and that is all we can afford. I have been rejected everywhere I have gone for prenatal care. I tried to go to an OB/GYN clinic through a community hospital, Bay Front Medical Hospital but was told I must come up with over $700.00 to get through the door, much less be seen by a doctor, and then make monthly payments.

"Senator, I tried every way possible to raise $700.00 but none of our relatives are doing any better financially than we are. I am four months pregnant and explained my situation but was told no $700.00, no care for the baby. They told me, 'You will have to eat hot dogs and beans for three of four months, if you care about your baby, you'll come up with the money.'

"I can't believe nobody cares what happens. A friend of mine's baby is due in seven weeks and has never had any prenatal care either because she is also "above poverty level." Something needs to be done soon to help us. We are not on welfare, but we are concerned about our unborn babies and have been rejected everywhere we go. This is a crime, we are not looking for handouts, just someone to see us through our pregnancies safely so we can sleep at night.

"I support you all the way and thank God for your concern for our innocent, helpless babies."

Finally, a young woman from Texas writes:

"...I would like to add more. I had a premature baby. My husband was out of work, and I was about 2 months pregnant when I tried to

get in to see a doctor. They would not help me because I did not have the money to pay. I then went to public health and they sent me to a government hospital. They would not let me in to see a doctor until I paid them $600.00 because they said I had to be lying about my income. I even showed them our tax papers, and they said they had to be a lie, but they weren't.

"I went to my mother-in-law and she took me to another doctor and paid the bill, but I was about 5 months pregnant then. My daughter was born weighing 4 pounds when I was 7 months along. She was born premature -- when I was pregnant I was having so much trouble then. When I would try to see a doctor they would say 'I am sorry, but we cannot help you because you don't have any money or life insurance. And we just cannot help you.' But some people just don't have a mother-in-law like I did. And they need help. Better help. My daughter is healthy but some babies aren't so lucky. So please help."

STATEMENT FOR HEALTH SUBCOMMITTEE HEARING ON
CHILD HEALTH CARE PROGRAMS
SENATOR JOHN D. ROCKEFELLER IV

October 2, 1987

Mr. Chairman, I also believe this is a well-timed and important hearing for this committee to hold. We have some tough work immediately ahead of us. The instructions facing us in the reconciliation process are to find ways to curb spending in Medicare and elsewhere. Fortunately, Congress made the decision earlier in the year to actually increase funds for maternal and child care. Today and over the next several weeks, we will consider specific ways to make some modest but crucial steps forward in this area.

When I was Governor of West Virginia, I made infant mortality a top priority. Along with other states with similar rates of teenage pregnancy and infant deaths, we made some tangible progress. Tragically, that progress appears to have been stalled in recent years. In fact, it appears that the situation may be once again worsening both in West Virginia and throughout the country.

It is impossible to feel anything but shame and sorrow when looking at this country's statistics -- in infant mortality, children born into poverty, and child health care -- as compared to other industrialized nations. To see that places such as Singapore and Hong Kong are ahead of the United States should challenge all of us to mobilize the resources and wherewithall to do far better in serving poor pregnant women and children.

Obviously, the federal deficit is a major barrier to expanding Medicaid, the Maternal and Child Health Care block grant, and other programs that help to produce healthy children with a chance of a productive life. But as study after study, experience after experience demonstrate, the cost of not spending more and improving services to help in the development of the first stages of life multiplies into the expense of addressing far more serious problems later on. We must make the investment in child health now.

Mr. Chairman, there are a number of members on this subcommittee who have records of great leadership in this area. I am grateful to them and to you for your own concern. We have impressive witnesses today whose expertise and recommendations will be invaluable to pursuing the work that faces us. I look forward to their testimony.

STATEMENT OF SENATOR JOHN HEINZ
COMMITTEE ON FINANCE
OCTOBER 2, 1987

MR. CHAIRMAN I WANT TO COMMEND YOU FOR HOLDING THIS HEARING TO EXAMINE CHILDREN'S HEALTH PROGRAMS. TODAY'S HEARING WILL FOCUS ON THE MANY DIFFERENT PROGRAMS AND POLICIES WHICH MIGHT PROVIDE A HEALTHY FUTURE FOR AMERICA'S YOUNG PEOPLE. POOR CHILDREN IN PARTICULAR FACE TOO MANY HANDICAPS, AND NEITHER NEED NOR DESERVE TO BE HOBBLED BY POOR HEALTH.

I AM PARTICULARLY PLEASED TO WELCOME DR. ROBERT CICCO, A NEONATOLOGIST FROM PITTSBURGH, PENNSYLVANIA, AND LEGISLATIVE CHAIRMAN OF THE NATIONAL PERINATAL ASSOCIATION. DR. CICCO'S EXPERTISE, AND THAT OF THE DISTINGUISHED PANEL OF WITNESSES, IS VERY WELCOME.

SINCE THE ENACTMENT OF MEDICAID IN 1965, OUR NATION HAS COME A LONG WAY IN IMPROVING THE HEALTH OF INFANTS AND CHILDREN. SINCE THAT TIME, THE U.S. INFANT MORTALITY RATE HAS BEEN HALVED. WE HAVE IMPROVED THE TECHNOLOGY THAT HELPS INFANTS WITH LOW BIRTH WEIGHT SURVIVE DURING THEIR FIRST WEEKS OF LIFE. BUT WE HAVE SEEN FAR LESS SUCCESS IN ACTUALLY PREVENTING LOW BIRTH WEIGHT INFANTS.

A STRATEGY TO PREVENT INFANT MORTALITY AND LOW BIRTH WEIGHT CHILDREN IS FAR PREFERABLE TO AN ATTEMPT TO COPE WITH INFANT MORTALITY. DURING THESE HEARINGS, WE SHOULD NOTE THAT THE U.S. RANKS 16TH IN THE WORLD IN INFANT MORTALITY, AND THAT A BLACK CHILD BORN HERE IN THE DISTRICT

OF COLUMBIA IS LESS LIKELY TO LIVE BEYOND HIS FIRST YEAR THAN A CHILD IN TRINIDAD.

JUST LAST YEAR CONGRESS TOOK A SIGNIFICANT STEP TOWARD PROVIDING CARE TO THE YOUNG AND VULNERABLE -- WE SNIPPED A FEW THREADS IN THE TIE BINDING MEDICAID ELIGIBILITY TO AFDC AND SSI, SO THAT POOR CHILDREN AND THEIR MOTHERS COULD HAVE ACCESS TO MEDICAID SERVICES. BY JANUARY OF 1988, TWENTY-FOUR STATES WILL HAVE TAKEN THIS OPPORTUNITY TO CHOOSE PREVENTION INSTEAD OF INTENSIVE CARE.

THE WITNESSES WILL TESTIFY ABOUT A BROAD RANGE OF ISSUES AND PROPOSALS INCLUDING COVERAGE OF CATASTROPHIC ILLNESS, ACCESS TO MEDICAL CARE FOR POOR MOTHERS AND CHILDREN, AND PRENATAL CARE TO PREVENT LOW-BIRTH WEIGHT AND INFANT MORTALITY.

AS A COSPONSOR OF S. 422 -- THE INFANT MORTALITY AMENDMENTS OF 1987 -- I LOOK FORWARD TO GAINING MORE INSIGHT ON THIS PROPOSAL TO FURTHER EXPAND MEDICAID ACCESS FOR POOR WOMEN AND THEIR CHILDREN. IF THERE ARE IMPROVEMENTS TO BE MADE TO THIS URGENTLY NEEDED LEGISLATION, OR IF MORE NEEDS TO BE DONE, I WELCOME THAT INFORMATION.

THANK YOU, MR. CHAIRMAN.

10/2/87

SENATOR DURENBERGER'S
MEDICAID AMENDMENTS FOR CHRONICALLY ILL CHILDREN
S. 1740

Senator Durenberger's proposal to amend Title XIX of the Social Security Act will allow states the option of extending Medicaid coverage to children with chronic illnesses and disabilities in low-income families whose income is below 185% of the federal poverty level.

ELIGIBILITY:

Any child that suffers from any chronic physical or mental illness, disability, or condition that causes an impairment or limitation of normal childhood activities, growth, or development; and

whose family income is below 185% of the official poverty line; and

whose health care costs are expected to exceed 125% of a state's average Medicaid expenditure per AFDC child.

(Children up to age 18, at state option up to age 21.)

BENEFITS:

These children will be eligible for the full range of benefits offered by the state's Medicaid program. Additionally, a state has the option to provide "enriched benefits" including all of the care and services described in sections 1905 and 1915 (home and community based services). This could include home health and personal care services, habilitation, respite care, and medical supplies and equipment.

Care and services under this option must be furnished in accordance with an individualized, written health care management plan developed under the direction of the designated case management agency. The plan should emphasize delivery of services in the least restrictive, most effective setting, with community integration.

HEALTH CARE CASE MANAGEMENT:

The State shall designate the most appropriate coordinating agency(ies) according to the individual needs of the children. The agency(ies) will ensure that comprehensive health care case management services are provided. The designated agency shall ensure:

a. that service coordination and case management services are provided to any child meeting the new Medicaid eligibility criteria, without regard to type of disability or illness;

b. that an individual written health care case management plan is developed in conjunction with the provider(s) and family;

c. that ongoing health case management is provided for the child;

d. the provision of services is monitored to ensure that they are timely and comprehensive and in accordance with the individual health care management plan;

e. that, if appropriate, the child's health care plan and course of treatment are coordinated with the child's special education and early intervention plan of care and services under Public Laws 94-142 and 99-457 and other relevant educational, medical and social services provided by public or private agencies;

f. ongoing evaluation of the child's course of health care and continuing need for extended Medicaid benefits is conducted.

PATIENT COSTSHARING:

All services are free to children in families with incomes that do not exceed 100% of the federal poverty level.

States shall impose a sliding scale premium for children in families with incomes between 100% - 185% of the federal poverty level. The premium shall not exceed 10 percent of the amount by which the family's adjusted gross earnings for the month, exceeds 1/12 of the federal poverty level for that family size. Family income will be adjusted to exclude uncompensated education, transportation, child care and other special costs incurred by the family due to the child's disability or condition.

PHASE-IN AND EFFECTIVE DATE:

The Amendments made by this Act shall be apply for calendar quarters beginning on or after

October 1, 1988 for eligible children in families with incomes below 100% of the federal poverty level;

October 1, 1989 for eligible children in families with incomes below 125% of the federal poverty level;

October 1, 1990 for eligible children in families with incomes below 150% of the federal poverty level;

October 1, 1991 for eligible children in families with incomes below 185% of the federal poverty level.

MEDICAID PAYOR OF LAST RESORT

Congressional Research Service
The Library of Congress

Washington, D.C. 20540

September 29, 1987

TO : Senate Finance Committee
Subcommittee on Health
Attention: Bruce Kelly

FROM : Mark Merlis
Analyst in Social Legislation
Education and Public Welfare Division

SUBJECT : Medicaid and the Maternal and Child Health Services Block Grant

In response to concerns about access to health care services for pregnant women and children, the 98th and 99th Congresses expanded coverage under Medicaid, the Federal-State health insurance program for specified groups of the poor, and approved higher appropriations for the Maternal and Child Health (MCH) Services Block Grant program. The 100th Congress is considering proposals which would further expand both programs. This memorandum provides background information on the programs and on the recently enacted changes, briefly reviews the status of children without health insurance, and summarizes current legislative proposals.

I. BACKGROUND 1/

The Senate Finance Committee has jurisdiction over two major programs providing financial assistance to States for the provision of health care to children: Medicaid, established by title XIX of the Social Security Act, and the MCH Services Block Grant, established by title V of the Act. Medicare, the other health program in the Act, serves very few children, chiefly those qualifying as a result of end-stage renal disease.

A. Medicaid

Medicaid is a Federal-State matching program providing medical assistance to low-income persons who are aged, blind, or disabled, members of families

with dependent children, and certain other groups of pregnant women and young children. Within broad Federal guidelines, each State designs and administers its own program. As a result, there is substantial variation among the States in persons covered, services offered, and methods of reimbursement.

At a minimum, States are required to provide coverage for the "categorically needy," generally persons who are receiving cash assistance under the Aid to Families with Dependent Children (AFDC) or Supplemental Security Income (SSI) programs. Most children receiving Medicaid benefits are also receiving AFDC. In addition, States may at their option provide coverage for other categorically needy groups who are not receiving cash assistance. One important group of the optional categorically needy is pregnant women and children with family incomes up to 100 percent of the Federal poverty level.

Finally, States may choose to provide Medicaid to the "medically needy," persons whose income or other resources are in excess of cash assistance standards but who are unable to pay the cost of their own medical care. The medically needy often become eligible through a "spend-down" process, meeting the resource levels established by the State after exhausting their funds on medical care costs. As of 1986, 38 States and the District of Columbia were covering some medically needy groups.

As with eligibility, service coverage is subject to minimum requirements, with coverage of additional services left to State option. For the categorically needy groups, all States must furnish basic inpatient and outpatient hospital, skilled nursing facility, physician, diagnostic, and family planning services. Optional supplemental services include dental care, prescription drugs, treatment in intermediate care facilities, home health care, and numerous other types of medical or remedial care. States may limit the scope of any services covered; they may, for example, pay for only a certain number of physician visits or inpatient hospital days in a year. Services must generally be uniform for all categorically needy beneficiaries; less extensive benefits may be made available to the medically needy.

In addition to other services, States must provide Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) services for beneficiaries under age 21. EPSDT is a program of screening, prevention, and treatment services for children. States are expected to conduct outreach efforts to encourage participation in EPSDT and to ensure coordinated follow-up care. For children

participating in the program, a State may provide optional services such as dental care even if it has elected not to furnish those services to other kinds of Medicaid beneficiaries.

States receive Federal reimbursement for most Medicaid service expenditures under a formula tied to State per capita income. The minimum Federal share is 50 percent; the highest share presently received by any State is 78.5 percent. For family planning services, the Federal share is 90 percent. Matching for administrative costs is generally at 50 percent, with higher rates for a few specialized activities. The Congressional Budget Office estimates that total Medicaid service expenditures under current law will reach $52 billion in FY 1988, of which 55 percent will be paid by the Federal Government.

B. Maternal and Child Health Services Block Grant

The current MCH Services Block Grant program was originally authorized in the Omnibus Budget Reconciliation Act of 1981 (P.L. 97-35) as a replacement for a variety of Federal-State programs serving women and children with low incomes or with special needs. These included a predecessor MCH program, SSI services for disabled children, lead-based paint poisoning prevention, hemophilia treatment centers, and programs addressing genetic diseases, sudden infant death syndrome, and adolescent pregnancy.

Under the block grant program, a portion of total appropriated funds (currently 10 to 15 percent) is "set aside," retained by the Secretary of Health and Human Services (HHS) for special federally administered programs of regional or national significance in such areas as maternal and child health improvement or research and training. The remainder is allocated to the States in proportion to each State's FY 1981 share of funds under the programs replaced by the block grant. States must contribute 75 cents for each Federal dollar received. The authorizing legislation provides for additional set-asides or supplementary allocations for special purposes, such as health screening of newborns, if appropriations exceed specified levels.

States may use MCH funds at their discretion for a variety of maternal and child health programs, including prenatal care, well-child clinics, immunizations, vision and dental screening, and family planning. States may also

include more specialized services for crippled children and other target populations.

II. RECENT PROGRAM TRENDS

A. Medicaid

After a brief period of fiscal constraint in the early 1980s, Medicaid legislation since 1984 has tended to expand slightly the populations eligible for coverage and to make it easier for States to design special services targeted to the needs of particular groups.

Eligibility expansion has taken three forms: mandatory coverage for some additional groups, optional relaxation of financial and other standards, and transitional coverage for persons losing cash assistance as a result of employment income. The following summary covers only provisions particularly affecting pregnant women and children.

1. New Mandatory Groups

The Deficit Reduction Act (DEFRA) of 1984 (P.L. 98-369) mandated that State Medicaid programs cover several groups for whom coverage had previously been optional. These included first-time pregnant women who would be eligible for AFDC if their child were born, and other pregnant women in two-parent families where the principal breadwinner is unemployed. In addition, States were required to cover all children born after October 1, 1983, who met AFDC income and resource standards, up to age 5.

The Consolidated Omnibus Reconciliation Act of 1985 (COBRA, P.L. 99-272) required that States cover pregnant women in two-parent families meeting AFDC income and resource standards even if the principal breadwinner was not unemployed. COBRA also required that States furnish post-partum coverage for eligible pregnant women until 60 days after the end of their pregnancy.

2. New Optional Groups

The effect of specifying a minimum birthdate in the DEFRA expansion of coverage for children was to phase in this coverage over a 5-year period ending

September 30, 1988. States could elect to cover all children under 5 at once, but only if they also covered all children under 18 eligible under the optional "Ribicoff children" rules. COBRA gave States the option of covering all children under 5 immediately, even if they had not chosen to cover all Ribicoff children. COBRA also permitted States to provide ongoing coverage for adopted children with special medical needs who were Medicaid-eligible prior to the adoption, without regard to the adoptive parents' income.

The Omnibus Budget Reconciliation Act of 1986 (OBRA, P.L. 99-509) permits States to offer Medicaid coverage to all pregnant women, infants up to age 1, and, on an incremental basis, children up to age 5, with incomes up to a State-established threshold which may be as high as 100 percent of the Federal nonfarm poverty level. Imposition of non-income resource standards is optional; any resource standard imposed must be no more restrictive than the SSI standard, for pregnant women, or the AFDC standard, for infants and children. States choosing to cover the new group are prohibited from lowering their AFDC payment levels below those in effect on April 17, 1986.

For pregnant women, coverage under this option is limited to pregnancy-related services and ends 60 days after the end of the pregnancy. Children would be required to receive the full scope of Medicaid services covered by the State. The new option took effect on April 1, 1987. Phased-in coverage for children age 1 to 5 begins October 1, 1987, and continues in 1-year increments until 5 year-olds may be covered in October 1990.

OBRA also permits States to establish temporary presumptive eligibility for pregnant women pending the completion of their application for Medicaid benefits. The purpose of this provision is to ensure access to prenatal care during the time it takes to complete a full eligibility determination.

Finally, OBRA allows States to cover respiratory care for ventilator-dependent individuals living at home who would be Medicaid-eligible if they remained in an institutional setting. Coverage of these individuals was previously permitted only under "model" waivers granted by the Secretary, or under provisions which would have required a State to provide much broader coverage in order to reach this specific population.

3. Transitional Coverage

Since 1974, States have been required to continue Medicaid coverage for 4 months after a family loses AFDC eligibility as a result of increased employment income or hours of work (or as a result of increased child support payments). In 1984, DEFRA added a requirement that coverage be extended an additional 9 months for a family whose countable income would be within AFDC limits but for the fact that the family's eligibility for certain income "disregards" had expired (the disregards are subtractions from earned income in AFDC eligibility determinations which allow a temporary continuation of cash assistance after an employment income increase). DEFRA also gave States the option of continuing Medicaid in such cases for an additional 6 months beyond the mandatory 9 months.

B. Maternal and Child Health

The initial MCH Block Grant appropriation for FY 1982 and FY 1983 was $373 million per year, as compared to the almost $455 million appropriated in FY 1981 for the programs the block grant replaced. While funding had grown to $478 million by FY 1986 (later reduced to $457 million by Gramm-Rudman-Hollings), this was still below FY 1981 expenditures in constant dollars.

P.L. 98-369 raised the permanent authorization level for the program to $478 million, and P.L. 99-509 (OBRA 86) authorized funding of $553 million for FY 1987, $557 million for FY 1988, and $561 million in succeeding fiscal years. The actual appropriation for FY 1987 was $478 million, later raised to $497 million by the supplemental appropriation bill signed in July 1987 (P.L. 100-71). The Administration's FY 1988 budget proposal called for continued funding at the $478 million level. The House has passed H.R. 3058, the FY 1988 Health and Human Services appropriations bill, which includes $535 million in MCH funding.

OBRA 86 provided that portions of any appropriation above the permanently authorized level were to be used for special projects. A fixed percentage of the excess is to be set aside and used by the Secretary for projects involving screening of newborns for sickle cell anemia and other genetic disorders (7 percent in FY 1987; 8 percent in FY 1988; and 9 percent in FY 1989). One third

of any remaining excess is to be used for demonstration projects promoting access to primary care or case management and community-based services for children with special needs.

III. UNINSURED CHILDREN

The Medicaid program has historically reached only a fraction of all children lacking health insurance coverage. Until the changes made by DEFRA, COBRA and OBRA, eligibility for children was generally tied to eligibility for cash assistance. Low eligibility standards in most States excluded many children in families with incomes below the official poverty level. The National Governors' Association reported in January 1987 that the average State's AFDC standard for a family of 3 was 48.9 percent of the official poverty level for a family of that size. Other children have been excluded because their families failed to meet non-income tests relating to family make-up or employment status. Table 1 shows the relative numbers of children in poverty and children covered by Medicaid from FY79 through FY86.

TABLE 1. Children in Poverty and Medicaid Coverage 1979-1986 (Numbers in thousands)

Year	Poor children	Poor children covered by Medicaid	Percent
1979	10,111	4,907	48.5 %
1980	11,764	5,525	47.0
1981	12,505	5,811	46.5
1982	13,647	6,429	47.1
1983	13,807	6,693	48.5
1984	13,419	6,622	49.3
1985	13,010	6,569	50.5
1986	12,876	6,676	51.7

Source: Congressional Research Service estimates, September 1987, based on U.S. Census Bureau March 1987 Current Population Survey data. Note that these numbers are based on self-reporting by a sample survey and are subject to error. Respondents may under report income and/or fail to report Medicaid eligibility.

Although the COBRA and OBRA changes have weakened the traditional eligibility links between Medicaid and cash assistance programs, there remain substantial populations of uninsured children who would not be reached even if

every State were to make full use of the new options made available by the amendments. These include:

- Children over age 5 who are in families with incomes between AFDC standards and 100 percent of the poverty level and who do not qualify as medically needy. If AFDC standards averaged half of the poverty level, as many as 2.8 million children aged 5 to 17 might have fallen into this group in 1986. 2/

- Children in families whose income is above 100 percent of poverty but who are still unable to afford insurance. A recent study by the Employee Benefits Research Institute found that of 34.8 million nonelderly Americans without health insurance coverage in 1985, 3 million had family incomes between 100 and 124 percent of poverty. An additional 7.3 million had incomes between 125 and 199 percent of poverty. 3/

- Children in families which may or may not be poor but which lack health insurance coverage because the parents' employers do not offer this benefit or the parents have failed to avail themselves of it. The EBRI study cited above found that 18.2 million of the uninsured, over 52 percent, were in families headed by full-time workers; 37.8 percent of the uninsured were in families with incomes above 200 percent of poverty. Sometimes the working parent or parents are covered by employer health insurance but cannot or do not purchase coverage for their children. EBRI found that 20 percent of all uninsured children lived with a parent who had employer-provided insurance.

IV. COVERAGE EXPANSION PROPOSALS IN THE 100TH CONGRESS

Legislative proposals in the 100th Congress would use several different approaches to expand Federally funded medical coverage of children. These include:

--General expansions of Medicaid eligibility for mothers and children.

--Special coverage provisions for children incurring extraordinary health care costs.

--Extended transitional coverage for families losing cash assistance as a result of employment.

There are also proposals for expansion of private health insurance coverage, such as S. 1265 (Kennedy), the Minimum Health Benefits for All Workers Act. 4/

As requested, the following is a summary of Medicaid eligibility proposals introduced in the Senate in this session. House bills are included only when there is a parallel Senate proposal.

A. General Coverage Expansion

S. 422 (Bradley et al.)

Medicaid Infant Mortality Amendments of 1987. This proposal builds on the coverage extensions enacted in 1986. The optional higher eligibility standard for pregnant women and infants, now limited to 100 percent of the nonfarm poverty level, could be raised at the State's option to as high as 185 percent of poverty. Coverage of children up to age 5 could be implemented immediately, instead of being phased in over a year period. Both these provisions would take effect October 1, 1987. In addition, States could phase in coverage under the higher standard for children up to age 8, with 6 year olds in FY89, 7 year olds in FY90, and 8 year olds in FY91. Introduced January 29, 1987, and referred to the Committee on Finance.

An identical proposal in the House, introduced as H.R. 1018 (Waxman), has since been incorporated in the Medicare and Medicaid Budget Reconciliation Amendments reported by the House Energy and Commerce Committee (H.R. 3188, Waxman), with a single substantive change. The effective dates for the higher income standard and the accelerated eligibility for children up to age 5 have been changed from October 1, 1987, to January 1, 1988.

S. 862 (Evans and Sanford)/H.R. 1831 (Downey et al.)

Partnership Act of 1987. This bill is a comprehensive revision of several welfare programs, including AFDC and Medicaid, establishing uniform benefit levels across States and increasing Federal responsibility. The provisions specifically relating to Medicaid are as follows.

States could implement the optional higher income standard (up to 100 percent of poverty) for all children up to age 5 as of October 1, 1988, rather than phasing in coverage on a year by year basis. States could then, in fiscal years 1989 through 1998, phase in coverage of children up to age 16. Resource standards for pregnant women and children could be no more restrictive than the standards for the Food Stamp program.

DHHS would be required to promulgate uniform national minimum standards for Medicaid services to be made available to eligible women and children; for pregnant women these services would have to include prenatal and post-partum care.

States would no longer have the option of establishing a Medicaid eligibility standard more restrictive than the SSI standard; all SSI eligibles would receive Medicaid. All States would be required to cover at least some medically needy groups.

Beginning in FY 1990, the Federal share in Medicaid service expenditures would increase 2 percentage points per year, up to a maximum of 90 percent. For services to pregnant women and children, the Federal share would be 80 percent in FY 1988, 85 percent in FY 1989 through FY 1991, and 90 percent in FY 1993 (the bill as introduced omits FY 1992). Nursing home and other long-term care services would remain subject to the Federal matching percentage in effect on the date of enactment. For any State Medicaid expenditures above FY 1987 levels and specifically attributable to provisions of the bill, Federal matching would be at 100 percent.

Introduced March 26, 1987, and referred to the Committee on Finance.

S. 1139 (Chafee)

MedAmerica Act of 1987. This bill would give States the option, effective October 1, 1987, of extending Medicaid eligibility to four new groups:

1. Individuals and families meeting a new income standard which could be set, at the State's option, as high as 200 percent of the nonfarm poverty level.

2. Persons unable to obtain health insurance because of a pre-existing condition.

3. Persons who have health insurance but who have exhausted some or all of the benefits under the plan.

4. Persons employed by businesses which have no more than 25 employees and which have been unable to provide employee health benefits at a reasonable cost.

The new options would be available only to States whose existing Medicaid programs met certain minimum standards relating to populations covered and scope of services. Benefits available to the new groups would be more restricted than under current Medicaid law and would be subject to mandatory cost-sharing. Beneficiaries with incomes exceeding 100 percent of the poverty level would have to pay monthly premiums not exceeding 3 percent of family income.

Introduced May 6, 1987, and referred to the Committee on Finance.

B. Catastrophic Coverage

S. 1283 (Weicker)

Medicaid Catastrophic Coverage for Children Act of 1987. This bill would mandate Medicaid coverage for disabled children under age 21 whose incurred medical expenses in a year are equal to the lesser of $10,000 or 10 percent of

the family's income. The limit for a family with more than one disabled child would be the lesser of $13,000 or 12 1/2 percent of family income. The State would be required to offer a full range of services to disabled children, including optional benefits not provided to other kinds of Medicaid beneficiaries. Services would be provided in accordance with an individual plan of care developed and periodically updated by a multidisciplinary team. The Federal matching percentage for services to the qualified disabled children would be 90 percent.

The new provisions would be in effect for fiscal years 1988 through 1992. During that period, States would be prohibited from establishing any Medicaid benefit or eligibility limits more restrictive than those in effect on May 27, 1987.

The Secretary of HHS would be required to conduct an ongoing study of the impact of the amendments, reporting annually to the Congress and making recommendations regarding continuation or modification of the new coverage no later than April 1992.

Introduced May 28, 1987, and referred to the Committee on Finance.

S. 1537 (Chafee et al.)

Care Management and Catastrophic Health Care for Children Act of 1987. This bill would provide catastrophic coverage to certain children through title V (the MCH block grant), rather than through Medicaid. Children eligible for coverage would be those who incur $50,000 or more in medical expenses during the first year of life, and who are in a low-income family or whose medical expenses exceed 10 percent of the family's adjusted gross income. Payment for services would be made directly by HHS, rather than by States, and would be issued according to Medicare reimbursement principles, except that payment for inpatient hospital services would not be subject to Medicare's prospective payment system or other inpatient limits. No payment would be issued for services covered by third-party insurance. The bill would authorize an FY 1988 appropriation of $375 million for the catastrophic coverage provision, over and above other appropriations for title V.

The bill would also provide supplementary block grant appropriations for the purpose of providing care management to children with special needs and

anticipated medical care costs in excess of $5,000 per year, including but not limited to those covered under the catastrophic care provision. Like the basic MCH block grant, funds would be allocated to States after a set-aside for projects of regional or national significance. Care management is defined as "advocacy on the child's and family's behalf to secure needed services and entitlements in accordance with a written care management plan." The bill would authorize an FY 1988 appropriation of $125 million for this purpose, again over and above the general title V appropriation.

Finally, the bill would require the Secretary of HHS to develop a special prospective system for inpatient hospital services to children, to be used both for the catastrophic care added to title V and for Medicare.

Introduced July 23, 1987, and referred to the Committee on Finance.

C. Transition Coverage

Two of the welfare reform proposals offered in the Senate this year have included specific provisions relating to continuation of Medicaid coverage after loss of cash assistance eligibility due to employment income.

S. 281 (Specter and Dodd)

Aid to Families and Employment Transition Act of 1987. This bill would extend Medicaid eligibility after a family member made the transition to unsubsidized employment under a Job Training Partnership Act (JTPA) program. Medicaid eligibility would continue for 15 months after the transition, unless the employer provided health insurance coverage earlier.

Introduced January 6, 1987, and referred to the Committee on Finance.

S. 1511 (Moynihan et al.)/H.R. 3148 (Gradison)

Family Security Act of 1987. This bill would require States to continue Medicaid for families losing cash assistance because of increased earnings for at least 4 months and not more than 9 months. (Currently, the 9 month extension is available only for families whose income is only slightly above AFDC limits.) States would be required to charge a premium for coverage in the final 5 months, and could provide the continued coverage only for families whose income is below 185 percent of poverty.

Introduced July 21, 1987, and referred to the Committee on Finance.

1/ The background discussion in this section is largely derived from two Congressional Research Service documents:

Federal Programs Affecting Children [coordinated by] Sharon House and Sharon Stephan. Committee print prepared for the House Select Committee on Children, Youth and Families. [Washington] 1987. (Medicaid section by Joseph A. Cislowski)

Medicare, Medicaid, and Maternal and Child Health Programs: An Overview of Major Legislation Enacted from 1980 through 1986 [by] Janet Kline, Jennifer O'Sullivan, and Joseph A. Cislowski. Background paper prepared for the use of the Committee on Finance. [Washington] 1987.

2/ Congressional Research Service estimate based on March 1987 Census Bureau Current Population Survey.

3/ Employee Benefits Research Institute (EBRI). A profile of the nonelderly population without health insurance. EBRI IB no. 66, May 1987.

4/ Details of these proposals may be found in U.S. Library of Congress. Congressional Research Service. Mandated Employer Provided Health Insurance. Issue Brief No. 87168, by Beth C. Fuchs, Aug. 26, 1987.

OPENING STATEMENT OF HON. GEORGE J. MITCHELL, U.S. SENATOR FROM MAINE

Senator MITCHELL. Good morning, ladies and gentlemen. This morning the Subcommittee will examine the programs under the jurisdiction of the Finance Committee which provide health care to our nation's children. Those programs are Medicaid and the Maternal and Child Health Block Grant.

It is our intention to review the current scope of these programs, in an effort to determine where they are falling short in providing adequate health care to the poorest of our nation's children.

The health of America's children overall is not good. Children Defense Fund studies conclude that major public health and social programs are inadequate to meet the national need created by persistent and widespread maternal and child poverty and loss of private health insurance.

The nation is not making progress in reducing the rate of infant mortality. The infant mortality rate in the United States, ranking among 20 industrialized nations, declined from sixth in the period from 1950–1955, to a tie for last, in the years 1980 to 1985. I think that bears repeating: In the most recent period for which such figures are available, the United States ranks last among 20 industrialized nations in its infant mortality rate.

Black infants continue to die at nearly twice the rate of white infants. A Black American infant born within 10 miles of the White House is more likely to die in the first year of life than an infant born in some parts of the Third World.

Members of this committee are aware of the crisis in health care for pregnant women and children and have supported improvements in Medicaid coverage in recent years. In spite of these efforts, there remain serious gaps in health care coverage for many, many children in this country.

According to estimates by the Congressional Research Service, in 1986 only 51 percent of poor children were covered by Medicaid. This is a disturbing fact which cannot be ignored.

The committee is well aware of the cost effectiveness of preventive health care for pregnant women and children. It is well documented that proper prenatal care significantly reduces the incidents of low birth-weight babies, one of the major causes of neonatal illness and death. Members of this committee, in particular Senators Bradley, Chafee, and Durenberger, have taken a lead in introducing legislation during the One Hundredth Congress intended to address the serious shortcomings in health coverage for children.

I look forward to the testimony to be presented by our witnesses today, in particular our colleague Senator Weicker, who has also been a leader in this area. It is imperative that we work together to ensure that all of America's children have adequate health care, regardless of the economic status of their families.

I am pleased to be joined by my colleague Senator Durenberger, who as I have just indicated has been one of the leaders in this area, who for six years served with distinction as chairman of this subcommittee and with whom all members of the committee look forward to working in this serious area.

I would like to now recognize Senator Durenberger.

OPENING STATEMENT OF HON. DAVID DURENBERGER, U.S. SENATOR FROM MINNESOTA

Senator DURENBERGER. Mr. Chairman, I thank you.

James Agee once said, "In every child who is born, under no matter what circumstance and of no matter what parents, the potentiality of the human race is born all over again."

Today's hearing gives us an opportunity to explore how we as a nation can help our children fulfill their potential, by giving every child a healthy start and by meeting the special health needs of children as they grow into young adults.

Last year the Federal Government spent over $35 billion on child health, nutrition, and protective service programs. We made tremendous strides in maternal, infant child, and adolescent health. Yet, tragic problems remain, and there are still serious gaps in our nation's health care system.

The lack of adequate health care not only affects the child's immediate well-being but has a life-long implication for the child's opportunity to develop into a mentally and physically healthy, competent adult. This is a great loss for our society and imposes tremendous, preventable costs.

Today, an estimated 11 million children, most of them from low-income families, are without health insurance coverage. These children receive 40 percent less physician care and half as much hospital care as their insured counterparts. And as a result, many health conditions which could be remedied become chronic for poor children because of this inadequate medical attention.

So it is time to develop a blueprint for the future that addresses all the special needs and concerns expressed by the Chairman and will be expressed by witnesses here today—a plan which includes an increased commitment to preventive health measures. We must increase our investment in the health of children today so they can fulfill their human potential tomorrow.

Even if we don't do this for humanitarian reasons, we must do it in our national self interest. Our nation's children are our future, and we will all be depending on them for a safe and secure world.

Yesterday I introduced a bill targeted to a special population whose needs often go unmet: chronically ill children in low income families. Without appropriate health coverage, the chronic condition is likely to become more severe and result in complications. This legislation will help children with juvenile diabetes, severe asthma, spina bifida, hemophilia, cystic fibrosis, and a variety of other conditions that limit a youngster's ability to engage in normal childhood activities.

The bill, S. 1740, allows the States the option of extending Medicaid coverage to chronically ill children in poor families so that they can receive the regular, consistent health care that will enable them to function at their optimum and avert costly hospitalization and emergency episodes.

Access to comprehensive health coverage will also free the parent to join the work force and not fear the loss of needed Medicaid coverage. It will protect poor families from the burdensome and often catastrophic cost of their children's chronic conditions.

The United Nations Declaration states: "Mankind owes to the child the best it has to give." I am delighted that this hearing today gives us an opportunity to explore and to renew our commitment to raising healthy children.

Senator MITCHELL. Thank you very much, Senator Durenberger.

As I indicated in my opening statement, three members of this committee have taken a particular interest in and demonstrated leadership in this area. In addition to Senator Durenberger and Senator Chafee, Senator Bradley is one of them, and we are pleased that he has been able to join us today.

Senator Bradley?

OPENING STATEMENT OF HON. BILL BRADLEY, U.S. SENATOR FROM NEW JERSEY

Senator BRADLEY. Thank you very much, Mr. Chairman, for holding this hearing. I hope this hearing will succeed in highlighting the deplorable circumstance of rising infant mortality rates. It is an issue that most Americans don't think about, but it is deplorable that the infant mortality rate in a city like Newark, New Jersey, is higher than in a country like Costa Rica. The fact of the matter is that there are a lot of near-poor women who can't get adequate health coverage during the prenatal period, and the result is low birth-weight babies and high infant mortality rates.

Mr. Chairman, a couple of months ago I wrote an article in a national magazine about this problem. And rather than making a lengthy opening statement, I would like to read you a couple of letters that I got as a result of that article. I received over 5,000 letters as a result of the article.

One is a letter from a woman in Tennessee—and each of these, I think, will put this issue in a very human perspective. She writes:

> You see, my husband and I recently ended a near tragic ordeal, much the same as you describe in your article. We were lucky, and I know God alone helped us and our precious baby son Joshua, because there was no help when we needed it, believe me. We are not the typically thought of welfare recipients; my husband is working, and when I found I was pregnant I was seeking work, since we had just relocated to Tennessee from Texas. All of a sudden I found myself pregnant and unhirable, after having been the manager of an engineering design firm. Prenatal care is expensive and we could not afford it on my husband's wages alone—$5.25 an hour, and no insurance.
>
> After calling endless State and local agencies seeking medical help and being told we're over-qualified to meet the guidelines—we were living on $742 a month—I finally got to a doctor when I was five months along.
>
> My mother-in-law scraped together $120 for the initial doctor's visit and then $65 for another checkup. Two months later, my son was born prematurely at seven and a half months gestation period. He weighed three pounds four ounces and was transferred to the East Tennessee Children's Hospital, to the Neonatal Intensive Care Unit where he remained for five long weeks. Thank God the hospital takes babies and children no matter their parents' ability to pay the debts incurred.
>
> God blessed us greatly, for we were able to bring our little miracle home in time for Christmas 1986. He remained attached to a heart and breathing monitor until July 26, 1987.
>
> After Joshua was born, we finally received Medicaid to pay the almost $30,000 in medical expenses. For anyone doubting the need for such care, I suggest they take a few minutes to visit the local neonatal intensive care unit. In my wildest dreams I would never have thought my baby would be in that situation. After all, I have worked since I was 16 years old and never asked for help from anyone.
>
> I will never understand how so-called "well educated, intelligent Government officials in Washington" can't get it through their heads. It is so much more inexpensive to help pregnant women receive proper prenatal care than it is to wait until the damage is done. When will other senators and lawmakers wake up and get some common sense?

And then, Mr. Chairman, a letter from a woman in Florida:

> I am now very fortunate to be four months pregnant; however the problems I am encountering are my worst nightmare. We are considered "over the poverty level." My husband earns $850 monthly and works very hard to make ends meet. We pay $475 monthly for rent, almost $200 monthly for utilities, and pay car insurance, groceries, and that's all we can afford.

I have been rejected everywhere I have gone for prenatal care. I have tried to go to the OB-GYN clinic through a community hospital, Bayfront Medical Hospital, but was told I must come up with over $700 to get through the door, much less be seen by a doctor and then make monthly payments.

Senator, I tried every way possible to raise $700, but none of our relatives are doing any better financially than we are. I am four months pregnant and explained my situation but was told, "No $700? No care for the baby." They told me, "You'll have to eat hot dogs and beans for three or four months. If you care about your baby, you'll come up with the money."

I can't believe nobody cares what happens. A friend of mine's baby is due in seven weeks and has never had any prenatal care, either, because she is also above poverty level.

Something needs to be done soon to help us. We are not on welfare, but we are concerned about our unborn babies and have been rejected everywhere we go. This is a crime. We are not looking for handouts, just someone to see us through our pregnancy safely so we can sleep at night.

Then, Mr. Chairman, finally, a letter from a young woman in Texas. She says:

I would like to add more. I was a premature baby. My husband was out of work and I was about two months pregnant when I tried to get in to see the doctor. They would not help me because I did not have the money to pay. I then went to Public Health, and they sent me to a government hospital. They would not let me in to see a doctor until I paid them $600, because they said I had to be lying about my income. I even showed them my tax papers, and they said they had to be a lie—but they weren't.

I went to my mother-in-law, and she took me to another doctor and paid the bill, but I was about five months pregnant then. My daughter was born weighing four pounds when I was seven months along. She was born premature. When I was pregnant, I was having so much trouble then. When I would try to see a doctor, they wouldn't say, "I'm sorry," but, "We cannot help you because you don't have any money or life insurance, and we just cannot help you." But some people just don't have a mother-in-law like I did, and they need help—better help.

My daughter is healthy, but some babies aren't so lucky as I to have a mother-in-law; so, please help.

Mr. Chairman, these three letters are samples of the over 5,000 that I received as a result of the article that I wrote. They clearly illustrate the need for my legislation. I hope that we will have a full hearing today and move to enactment, so that many of these women could be covered and we wouldn't have so many premature, low birth-weight babies with a high probability of infant mortality.

Senator MITCHELL. Thank you very much, Senator Bradley.

Our first witness was scheduled to be Senator Weicker. He has been unavoidably detained and is on his way, so we will begin with the first panel. When Senator Weicker arrives, we will interrupt the panel to permit him to testify.

The first panel will include Dr. Karen Davis, Chairman of the Department of Health Policy and Management at Johns Hopkins University in Baltimore, Maryland; Ms. Sara Rosenbaum, Director of Child Health, Children's Defense Fund in Washington, D.C.; and Dr. Robert Cicco, Legislative Chairman, National Perinatal Association in Pittsburgh, Pennsylvania.

Good morning, Dr. Davis, Ms. Rosenbaum and Dr. Cicco. We look forward to your testimony. We will begin in the order as listed on the committee witness list. I will state, for your benefit and for the benefit of future witnesses—I know Dr. Davis has testified here many times, as have others; but for the benefit of those who have not—under the committee's rules, each witness may submit a written statement which will be printed in full in the record. We ask the witnesses, in their oral remarks before the committee, to sum-

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marize their statements, selecting those points they deem most important, and to limit their oral remarks to five minutes or less, to permit questioning by the members of the committee. The panel of lights before me is an indicator to you of how much time you have. When the green light is on, it means you can keep talking; when the yellow light comes on, it means you have a short time to wrap up; and when the red light comes on, it means stop, as it does in other areas of our life.

Before we call on Dr. Davis, we are pleased to be joined now by Senator Chafee, who, as I indicated in my opening remarks, has been one of the leaders in this area, a distinguished member of this subcommittee and someone who has contributed a great deal to health policy in our nation.

I would like to call on Senator Chafee for any opening remarks he may have.

OPENING STATEMENT OF HON. JOHN H. CHAFEE, U.S. SENATOR FROM RHODE ISLAND

Senator CHAFEE. Well, thank you very much, Mr. Chairman, and I apologize for being late. There is an amendment on the floor that I am involved with, so I had wanted to make a couple of comments on that.

I just want to commend you for holding these hearings on this critical issue of children's health care. I must say I express some frustration at the fact that we spend in this Congress a good deal of time talking about better access to health care services, but so far not a great deal has been accomplished. I know that is as painful to you as it is to me and all members of this subcommittee.

Each year we make some small progress during budget reconciliation, but it has been limited, and I am disappointed that there doesn't seem to be an apparent willingness on the part of a whole host of parties that are involved with this to go further. I am disappointed that we aren't able to focus our energies and time and resources on truly identifying and addressing the health care crisis that in my judgment we face.

This committee—that is the Finance Committee as a whole—has jurisdiction, as we know, over three of the most critical health care programs in this country: Medicare, Medicaid, and the subsidy we provide for businesses for providing health care benefits to their employees.

Last year the expenditures under Medicaid amounted to $74 billion. Medicaid cost $24 billion, and the tax subsidy program, what we call a "tax expenditure" in this fancy language of the Finance Committee, resulted in about $32 billion in lost revenue. Yet, with all that spending, we still have children who receive no health care, pregnant women with no proper prenatal care, disabled individuals who are forced to live away from their families and communities, families financially devastated and torn apart because of illness, and 37 million people with no health insurance at all.

So we are here today, thanks to your leadership, Mr. Chairman, to address some of these issues and, hopefully, to make some progress. And of course, that involves the Administration. I am glad that we have some Administration witnesses.

I have introduced two proposals that will be discussed today: MedAmerica and the Children's Catastrophic, and I have cosponsored others.

As we begin the process of reconciliation, it is my plan to offer amendments based upon the MedAmerica, the concept of allowing individuals to purchase Medicaid insurance.

So we know what the problems are, and I hope today we can come up with some solutions. And I can vouch for you, Mr. Chairman, with your excellent leadership.

Senator MITCHELL. Thank you very much, Senator Chafee.

Dr. Davis, welcome. We look forward to hearing from you.

STATEMENT OF KAREN DAVIS, PH.D., CHAIRMAN, DEPARTMENT OF HEALTH POLICY AND MANAGEMENT, JOHNS HOPKINS UNIVERSITY, BALITMORE, MD

Dr. DAVIS. Thank you, Mr. Chairman, for this opportunity to appear before you today and to participate in this very important hearing on child health.

Recent improvements in Medicaid coverage are helping many mothers and children from our poorest families receive needed health care; yet, two major problems remain: First, millions of low income infants and children remain uncovered by Medicaid and face major barriers to the receipt of needed health care services; second, uncovered expenses of chronically ill children can inflict serious financial hardships on families. Today I would like to discuss these two major problems and offer some short term and longer term policy actions to improve access to basic health care for poor children and coverage of catastrophic expenses for all children.

Current health insurance coverage fails to assure access to basic health care services for poor children. Six million children with incomes below the poverty level are without Medicaid coverage. Only half of poor children are covered by Medicaid.

Medicaid coverage has been very important in improving early or prenatal care. This care is important to detect conditions such as anemia and high blood pressure, that need to be corrected early on in pregnancy.

In 1963, 58 percent of poor women received care early in pregnancy. By 1970, 71 percent of poor women received early or prenatal care, in part as a result of the Medicaid program. Infant mortality has declined by half since Medicaid was enacted; however, many disparities remain.

But there are also problems with older children, not just pregnant women and infants. Poor children suffer many chronic conditions, many of which were mentioned by Senator Durenberger, that may lead to serious problems. These include things like asthma, spina bifida, and chronic recurring conditions that require medical care services.

Children who are covered by Medicaid receive better care than poor children who are not currently covered by this program.

The Congress expanded Medicaid coverage for poor infants and young children and pregnant women, in 1984 in the Deficit Reduction Act, and again in the 1985 Comprehensive Omnibus Reconciliation Act and the 1986 Omnibus Reconciliation Act. As a result 9 million children and 800,000 pregnant women who are receiving assistance under this program. But further steps are needed to

expand coverage to children from the ages of 5 to 18 and other low-income children.

The second problem I would like to address is catastrophic illness among children, particularly those with ongoing chronic afflictions, and the financial burden that these illnesses can incur. Many times we focus on the problems of neonatal intensive care and premature infants that certainly can result in devastating financial problems, but there are also many chronically ill children who need assistance. There are 2.2 million families who have seriously impaired children; these are children with diabetes, leukemia, sickle cell anemia, cystic fibrosis, and other conditions.

Impaired children average 22 physician visits annually and 1.7 hospital discharges per child, compared with 4 physician visits a year and 0.3 hospital discharges for the non-disabled child. So we are talking about rates that are at least five times higher for the chronically impaired child.

Annual expenses exceed $10,000 for the most severely impaired children—and these are not one-time expenses but expenses that occur year after year.

Ten percent of impaired children are uninsured; 20 percent of poor disabled children are uninsured. Medicaid covers only 60 percent of poor disabled children.

Private health insurance, even when it exists, is not sufficiently comprehensive. We need to take major steps to expand Medicaid coverage for all children, including those 5 to 18, up to the Federal poverty level, and to improve our employer health insurance plans to cover not only prenatal and infant care but catastrophic insurance coverage for those working families.

Thank you.

Senator MITCHELL. Thank you very much, Dr. Davis.

Before calling on Ms. Rosenbaum, I want to welcome our distinguished colleague Senator Rockefeller to these hearings and ask whether Senator Rockefeller has an opening statement he cares to make at this time.

Senator ROCKEFELLER. I do, Mr. Chairman, but I will put it in the record. I am not particularly happy about the fact that Hong Kong and Singapore are doing better than we are in terms of infant mortality. I think your leadership and that of Dave Durenberger and John Chafee is crucial, and I am glad we are having these hearings.

Senator MITCHELL. Thank you very much, Senator.

Ms. Rosenbaum, welcome.

STATEMENT OF SARA ROSENBAUM, DIRECTOR, CHILD HEALTH, CHILDREN'S DEFENSE FUND, WASHINGTON, DC

Ms. ROSENBAUM. Thank you for this opportunity to testify.

I am going to move right to our recommendations, since my time is short.

We think the time has come to simply put into place a uniform program of public health benefits for low income children and families. Like Senator Chafee, we believe that the issue has been debated so long and so exhaustively that, until we can improve and strengthen the private insurance system to reach more families,

the time is long overdue for a uniform set of residual public benefits.

At a minimum, during this reconciliation process, we think that the following actions are vital:

First is enactment of S. 422, the Infant Mortality Amendments of 1987, which has been introduced under the leadership of Senator Bradley, and is cosponsored by all of the members present and by a majority of the Finance Committee.

The bill would do several things. As Senator Bradley has noted, it would permit States to dramatically strengthen their Medicaid coverage of pregnant women and in fact bring the program in conformity with WIC, the Supplemental Feeding Program for Women, Infants, and Children. The two programs together have been enormously successful, and the eligibility standards permitted under S. 422 would allow the programs to work better together.

We would like to note that, while we would prefer that Medicaid benefits under the new program be extended in accordance with the standards that govern WIC—that is, without charge to the family—we understand from the National Governors Association and from a number of States that, without some ability to impose a modest premium requirement, a number of States perceive difficulties in adopting the program. Thus, we do support a slight modification of the original bill to permit States at their option to impose a modest premium on pregnant women and infants with incomes over the Federal poverty level. I believe that Senator Bradley is now drafting such a modification to this bill.

We also want to stress that Senator Bradley's bill does not confine itself to infancy but in fact strengthens coverage during early childhood. This is particularly true for the very poorest children, who were added to Medicaid in 1984 under the Deficit Reduction Amendments—that is, children living under the State poverty level—and who will lose coverage beginning in 1988 in some 17 States if their eligibility is not extended. These are the poorest of the poor children. We calculate that the incremental cost in preserving these children's eligibility in the 17 States that don't already cover them is about five hundredths of one percent of the States' Medicaid outlays. These are not the kinds of costs that should give anybody pause. There is no question that the older children's provisions in S. 422 should also be included in the reconciliation package.

In addition, of course, we hope that the Senate will include S. 1740 in reconciliation. As Dr. Davis has noted, the children with chronic illnesses and disabilities show the greatest utilization deficits.

We also strongly endorse immediate Senate action on Senator Chafee's MedAmerica bill, to allow any low income family that doesn't have access to Medicaid to buy coverage, and to allow persons who have disabilities to buy Medicaid coverage at cost.

We also endorse Senator Chafee's Catastrophic Illness Bill. In the absence of an insurance plan for catastrophically ill children, some program must be put into place to help families meet their children's high costs. And the capacity of Title V Maternal and Child Health Programs to respond to all chronic illnesses and disabilities has to be strengthened.

Finally, I would like to note that two months ago an infant in Mississippi died because the State, like most others, has failed to implement a guarantee enacted by Congress in 1984 which provides Medicaid coverage during the first year of life for babies born to Medicaid mothers who continue to remain eligible for benefits. Like most States, Mississippi failed to implement the program. As a result, mother of a baby who was never furnished with a Medicaid card and who was dying, from what in retrospect appears to have been meningitis, sought care to no avail. The baby had not been given its own Medicaid card, and thus physicians refused to treat the infant since there was no way to bill for services. The baby was found dead in its crib two days after it was first taken ill and the time the mother first sought care, and it was buried without autopsy.

Had Mississippi done what private insurance plans do—namely, permit the mother to use her own insurance card to purchase services for the infant until the baby's card arrived—we believe that the baby would be alive today.

We therefore ask that the statute be slightly amended to explicitly require, as HCFA has failed to do, that States permit mothers to purchase services for their infants, during their automatic eligibility period, through their own Medicaid cards until such time as their babies' cards arrive in the mail.

I want to note that this case was brought to our attention not by a local advocacy organization but by the Mississippi Health Department itself. It is an unmitigated tragedy that should not happen in any other State.

Thank you.

Senator MITCHELL. Thank you, Ms. Rosenbaum.

Dr. Cicco, welcome. We look forward to hearing from you.

STATEMENT OF ROBERT CICCO, M.D., LEGISLATIVE CHAIRMAN, NATIONAL PERINATAL ASSOCIATION, PITTSBURGH, PA

Dr. CICCO. Thank you, Mr. Chairman, for this opportunity.

I will speak not from my written testimony, which is on the record, in light of events that have occurred in the last few days.

I speak to you today as a representative of the National Perinatal Association, an organization comprised of 10,000 members who, like myself, work day in and day out caring for pregnant mothers and sick infants. I join NPA not as a physician but as an individual who cares for mothers and babies. The organization is multi-disciplinary and is composed of many of the health care team, with one common goal—that being the welfare of mothers and babies.

As you will read in my written testimony, today is a special day for me. Thirteen years ago I celebrated the birth of my first son seven and a half pounds, term, healthy. The dreams that I had for him have been fulfilled. Tuesday night this week I explained to a mother that her child would die. Her child was one and a half pounds, about the weight of this book. Her child was born 14 weeks early. She was unable to obtain prenatal care. Her husband had a job but could not afford health insurance. They were not eligible for Medicare. Her dreams and hopes were the same as yours for

your children and mine for my children. Her dreams will not be fulfilled; her dreams died Tuesday night.

Earlier this week I also discharged a child about the same birth weight, a medical success—kept alive, sent home healthy, one and a half pounds—a success until one considers that the cost was over $110,000, and the mother underwent treatment during the course of the child's hospital stay for the depression that she went under, seeing the things that we had to do to keep her baby alive.

Some of these cases that I mention are not preventable. We know this. Despite the best of health care, the cases will not be prevented. However, we still owe to these families at least a chance to deal with the emotional stress without having to worry about the financial stress, through some form of catastrophic health care. For, even the best of insurance companies cannot cover the entire cost of neonatal intensive care.

Unfortunately, many of these cases are in fact preventable. We know this from statistics from other countries, who do do better than we do. We have fallen behind Japan not just in radios and VCRs but in the saving of their children's lives. They have gone ahead of us, not so much by improving neonatal intensive care but by preventing intensive care from occurring. They have done this by achieving better access to health care, and this is a goal that we have to reach in this country. It will be a long range goal; it will not be an easy measure.

The measures that we are talking about today are steps that we can take, and I hope that the Federal Government will be able to exert leadership. It will, however, require input from not only the public sector but also the private sector.

This is a cost-effective mechanism. The bills that we see from children who leave intensive care are more than outweighed by the cost savings that will occur by providing preventive health care.

The job that we do in the neonatal intensive care nursery is quite important. I love the work that I do, and I love the children that we care for; however, no one—not myself, not the National Perinatal Association, not anyone who is involved in this work—believes that health care will be improved through neonatal intensive care. In the neonatal intensive care nursery we are fighting against a stacked deck, and the only way to unstack this deck is to be able to enact preventive measures such as we are considering today.

Thank you.

Senator MITCHELL. Thank you very much, Doctor, for a very compelling testimony.

We will begin the questioning in the usual manner; that is, the order of questioning will be in the order that members appeared here. I note that a vote has just begun, and as Senator Chafee wrote, go ahead and vote and return in hopes that we can keep the hearing going consistently.

Dr. Davis, in your testimony you state that half of the children from families below the poverty line are not covered by Medicaid. Do you know or have any way of knowing how many of those children are dependents of persons who are employed, either full or part time?

Dr. DAVIS. We know that there are about 7 million uninsured children who are in working families; that is out of about 37 million who are uninsured. But we don't know exactly how many of those are poor. I don't have that data.

Senator MITCHELL. Legislation is pending before the Congress that would mandate employers to provide health benefits. Do you believe that would address a significant part of the problem? And do you support that legislation?

Dr. DAVIS. I think that legislation is very important. As I said, it would very much help with the catastrophic expense problem of these 7 million children who are in working families.

There is currently a bill that Senator Kennedy and others have introduced that would provide comprehensive prenatal infant and delivery care, and would put a ceiling on the the maximum out-of-pocket expense that any family would bear. That would be a very important step, and one could even take a more modest step than that by simply having the catastrophic ceiling and the comprehensive prenatal infant care. Senator Kennedy's bill, I understand, would add about 55 cents an hour to the labor costs of employers. A more modest bill could be done for about 20 cents an hour. A comprehensive maternal package added to a health insurance plan would run about $69 per family per year, so we are talking about relatively modest expenditures to do this. I think it would be an important step to address the 7 million children in working families that are uninsured.

Senator MITCHELL. What is the source of that estimate?

Dr. DAVIS. Those estimates come from the Congressional Budget Office.

Senator MITCHELL. I see. The $69?

Dr. DAVIS. Right, per family per year. It was originally done by a health expert by the name of Gordon Trapnell and supplied to the Congressional Budget Office.

Senator MITCHELL. Ms. Rosenbaum, do you have an opinion on that legislation?

Ms. ROSENBAUM. Yes. We support Senator Kennedy's legislation. Obviously, we would prefer to see it enacted in its more expansive form since, in the form that Dr. Davis has just described, coverage would end at birth, as I understand it, except for catastrophic illnesses and well baby care. Beyond that, of course, there are many children, and we estimate it is about a third of the low income uninsured children whose parents are not attached to the work force, for one reason or another, who are going to continue to need public health assistance.

If the Kennedy bill in its scaled-down version is enacted, then there will be a terrific need still for a bill, for example, like Senator Durenberger's, because these families, unless their children become desperately ill, will not have access to ongoing primary care; there will still be a need for Senator Bradley's bill for the millions of children in families who are not connected to the work place and for the pregnant women who are not connected to the work place. But we are supportive of Senator Kennedy's bill.

Senator MITCHELL. Dr. Cicco, in your written statement, you state that in 1984 more than 20 percent of all births in the United States were to women who failed to receive prenatal care during

the first trimester. Do you believe this is attributable to lack of funding for prenatal care, or simply a lack of education, or are they related? Is it both?

Dr. CICCO. They are both. The lack of funding has been there, but the lack of implementation for that funding I believe is also there. Some of the funds that I believe have been earmarked for provision of prenatal care have not been utilized necessarily in the proper way. There are still people in my home city of Pittsburgh, for instance, where black infant mortality is one of the highest in the country, that our feeling was that the care, although it was present, oftentimes was not accessed because it was not being delivered in a way that it was providing the quality that other people in the society were obtaining.

There needs to be work both on not only the funding but the quality availability of that care to the segment of the population we are trying to hit.

Senator MITCHELL. Thank you very much.

Senator Durenberger?

Senator DURENBERGER. Thank you.

I appreciate George shifting from what we all agree on to what we might not all agree on, because it gives me an opportunity to say something about responsibility.

There is a proposal in Congress to expand catastrophic health care coverage for the elderly in this country, and we are all cheering because it has an income test factor to it. But then, along comes the great bonanza of a freebee, and the trade-off to income-testing your access to the system is that you are going to get free drugs, but only after you pay the first $600 or $700. Again, a system that discriminates against those who are less well off.

There is also a proposal that, if the States save anything—which they will—on Medicaid by going to catastrophic, then the savings have to be plowed back into elderly health care. Again, there is nothing wrong with it, it is a very important benefit, but I don't see any reflection of the fact that we are putting an awful lot of resources in this country into health care through the Medicare and the Medicaid systems for older persons.

You have all reflected on the value of the mandated employer insurance. I just have to say, that if we have got another $500 billion a year to spend on health care, okay, that is fine; but I don't think we do. The States are paying 42 cents on the dollar right now to doctors and hospitals for Medicaid. All of these stories we heard here today are about States not standing up to their responsibility; but a lot of States don't have the capacity to do so.

It strikes me that if Lee Iaccocca can get $380 a month in tax-paid health insurance, we are going about this employment subsidy in the wrong way. Before we mandate all of that kind of activity on every employer in the country, maybe we ought to be looking at different ways to use some of those subsidies.

I don't have a question. I have to go off and vote, but I would hope that this line of questioning which deals also with the broader issues rather than the specific can be carried by those of us who really care about children in this society.

I don't think it is a matter of taking anything away from the elderly or away from employed persons to give to children; it is a

matter of focusing what we currently do. And all of you have been very involved in formulating health policy here in this country and know what I am talking about. I trust that you will continue, on behalf of children, to ask those of us who are adults in the society to look at the way we misuse the benefits that we already get from the system, and to help those of us who are trying to reorient those benefits.

Thank you. We will all be back in a couple of minutes.

[Whereupon, at 10:52 a.m., the hearing was recessed.]

AFTER RECESS

Senator CHAFEE. How far have we gotten? Has Senator Mitchell asked his questions?

Dr. DAVIS. Yes.

Senator CHAFEE. He has completed? And Senator Durenberger?

Dr. DAVIS. Yes.

Senator CHAFEE. He has completed.

Let me ask Dr. Cicco: I know this is guesswork, but what percentage of the low birth-weight babies are born could be delivered at full weight and healthy weight if there was proper prenatal care, would you guess?

Dr. CICCO. I think there is a very real chance that we could reduce the incidence of low birth-weight babies or the incidence of prematurity in this country from its current 7 percent down to 3 to 4 percent.

Senator CHAFEE. In other words, you think you could cut it in half?

Dr. CICCO. Yes.

Senator CHAFEE. Ms. Rosenbaum, do you agree with that?

Ms. ROSENBAUM. Yes. Certainly, in 1979 the Surgeon General felt that by 1990 there was no reason why we couldn't reduce low birth-weight to 5 percent of all births, yet we are 25 percent over the mark. So, we will not even reach this modest articulation of the goal.

Senator CHAFEE. How about Dr. Davis?

Dr. DAVIS. I don't have a comment on that.

Senator CHAFEE. No guess?

Dr. DAVIS. No.

Senator CHAFEE. I must say that is a startling statistic. If you are right, even close to right—in other words, if you don't cut it by 50 percent but if you cut it by 15 percent—financially, the Federal Government would come out way ahead.

I have been working with a figure—whether it is accurate or not—of proper prenatal care for a mother could cost $700. Is there any significance to that figure? Am I right?

Dr. CICCO. Probably somewhat more than that.

Senator CHAFEE. Do you think it is more than that?

Ms. ROSENBAUM. Well, including the delivery it would be higher, but the Institute of Medicine in 1986 put the actual cost of the package at a little over $400. We have used estimates of $700, which include nutritional supplementation. We estimate that an entire maternity package would cost anywhere between $2,500 and $3,000.

Senator CHAFEE. And, on the other hand, I don't find the figure you used, Dr. Cicco, of $110,000 to save a low birth weight baby out of range. Would you? Would that be very high, would you say?

Dr. CICCO. That is higher than the average. The average charges or costs to a child who comes through the premature nursery are lower than that, but they are still upwards of $25-30,000. But some of those babies are babies who require very short hospital stays; a small segment of those babies are children who require months and months of hospital stays and sometimes will incur charges of greater than $200,000.

Senator CHAFEE. Dr. Davis, you are supportive of the concept of the Medicaid buy-in for the so-called "uninsurables," and that is involved with the legislation I have which we call MedAmerica which permits this buy-in of the Medicaid. The question is: If we change that law and make it a State option, do you think many States would opt to do it? Or do you think it would be so small, it would be practically a demonstration project?

Dr. DAVIS. I think we get a variable response when States are given an option. I think that what we have seen, in giving the States the option to bring in pregnant women and young children up to the Federal poverty level, is that you only get a third to half of them willing to do it. On the buy-in, since there would be less of a fiscal impact on the States, they might be more willing to do it. So, I think that a three-pronged approach, having some minimum standards that the States must do, having some minimum standards that employers must do, and then filling the gap with buy-in, is certainly the right approach.

I personally would favor some subsidies of the Medicaid buy-in if you are below 150 percent of poverty, for example.

Senator CHAFEE. One of the witnesses mentioned Connecticut. You listed a series of States and had Connecticut as sort of one of the ones not behaving themselves. That seems odd to me. Do you remember who that was that mentioned Connecticut? It is not that I am carrying the cudgel for Connecticut, but Connecticut usually does——

Dr. DAVIS. I think, in terms of States that have acted to bring the coverage of pregnant women and infants up to the Federal poverty level, Connecticut is one of the States that is expected to do it later on this year, but has not yet done it. However, I don't think I had a specific reference to Connecticut.

Ms. ROSENBAUM. I am not sure where it may have come up. Certainly, Connecticut is a State whose public health programs are probably less than one would expect in a State. Being a native Connecticutite, I can say that Connecticut's programs are less than one would expect in a State as well-to-do as Connecticut is.

Senator CHAFEE. I think Connecticut is usually listed as the wealthiest State in the country.

Ms. ROSENBAUM. Yes. And for example, Rhode Island and Minnesota, Massachusetts and Michigan now have universal maternity programs for women with incomes under 200 percent of the Federal poverty level. Connecticut does not. Those four States have outstripped Connecticut in a number of ways.

Senator CHAFEE. I see Senator Weicker, and I see that Connecticut is going to be straightened out very quickly. [Laughter.]

Although, I also did see on this list Minnesota, too.

All right. Ms. Rosenbaum, I want to thank you and CDF for all the help you have given us in developing the Medicaid proposal and the MedAmerica proposal. What do you think the States will do if there is an optional thing?

Ms. ROSENBAUM. Well, we certainly have been heartened by the response to the 1986 Amendments. Far more States than have ever picked up an option before have picked up the new option to cover poor pregnant women and infants.

I think that there are certain groups of individuals and families that States appear to be extremely interested in covering. The advantage of MedAmerica is that benefits are offered in what is akin to an insurance plan, as opposed to more attenuated grants programs or pooling programs, or what have you. There may be a number of States that are now covering certain individuals under less than insurance programs, who would convert their programs; there would be other States who would expand and strengthen their own indigent health efforts.

So I think the proposal has been made at a very opportune time, because there is a great deal of ferment at the State level, and I would expect a reasonable State response to the option.

Senator CHAFEE. Let me ask you a final question: We have been here many years—you have testified, CDF has testified, Dr. Davis—and there is nothing particularly new as far as the statistics or the situation; what is the matter? Why don't Americans seem to get more excited over this? How can we have a situation where 37 million Americans have no health insurance, and where we have, as Senator Rockefeller pointed out, an infant mortality that is the lowest of the 20 industrial nations? Is it up to this committee to use this place as a bully pulpit and do more to sound the alarm? What is the matter, anyway?

Dr. DAVIS. I think it is a matter of political action; I think we know in terms of the research how important it is to have better coverage of children up to the age of 18 and pregnant women.

Obviously, the budgetary situation has been the main stumbling block. It is expensive to have complete coverage of the entire 37 million who are uninsured. But it strikes me there is an incremental way of dealing with that problem that is quite reasonable in even a tight budgetary situation, and that is to take incremental steps for the poor under Medicaid, and also——

Senator CHAFEE. What is the first step you would take?

Dr. DAVIS. The Congress has already taken some small steps by——

Senator CHAFEE. What we did last year in the Reconciliation?

Dr. DAVIS. Yes, requiring the States to cover pregnant women and infants gradually up to the age of five under AFDC standards and giving them the option up to 100 percent of poverty. I think the maximum age needs to be raised from five to eight, and then actually on up over time.

So, making sure we don't lose those children under Medicaid in October of 1988, when the coverage would drop is the most important thing to do. So, I would start by worrying about that group, 5

to 18; some of them are even below the State AFDC standard, but are not covered by Medicaid.

Senator CHAFEE. Ms. Rosenbaum?

Ms. ROSENBAUM. I agree completely with Dr. Davis. I also would add that I don't think we have to choose; I think that we don't have to decide that we are going to move this year on pregnant women and then another year on children and maybe go from 50 percent to 100 percent to 150 percent. If one looks at the overall costs of a residual, gap-filling approach that would put into place over a several-year period a program for families below 200 percent of the Federal poverty level, the cost is actually very modest particularly comparing to what the Nation spends in tax expenditures on private insurance.

Senator CHAFEE. This is with the Medicaid?

Ms. ROSENBAUM. Yes, through a program, until such time as we can figure out—if that is the course we choose—how to beef up the private system. We cannot wait for the private system to right itself without strengthening the best public health program we have for families.

Senator CHAFEE. Which is Medicaid?

Ms. ROSENBAUM. Which is absolutely Medicaid. In fact, there are data that show that low income children who have illnesses receive more health care through Medicaid than children who are privately insured, because the coverage is more comprehensive and deeper and not subject to arbitrary limits.

Senator CHAFEE. Dr. Cicco?

Dr. CICCO. I would add to that, Senator, only that when you ask why this is not a more talked-about problem, part of the problem is that the largest segment who are involved in infant mortality are also involved with a multitude of other socioeconomic problems are not able to speak out. And those who are not in that group don't consider it a problem until they happen to have a baby who is born premature. Then you get their involvement in a parent group, then you get them speaking out. But the average middle class American does not think about the possibility of having a premature baby.

I can't tell you the number of times when a middle class mother will have a baby born prematurely, in the nursery, will make the statement, "I never thought this would happen to me." When it does happen, people come out of the woodwork, people who have had premature babies; but it is not something that is on the top of their mind at the time that they become pregnant. Some form of public awareness that this is in fact a problem, which I believe can stem from the public sector, I think would be very important.

We all have to realize, too, that the largest segment, again, the poor people of this country, may be out of work and not involved with a lot of the private sector, and we need to make the private sector realize that this is an important part of the country that will need to be dealt with, because the cost of the care that these children require and the outcomes of these children impact on everybody in this country.

Senator CHAFEE. Senator Rockefeller?

Senator ROCKEFELLER. Mr. Chairman, just one basic question, perhaps for Ms. Rosenbaum or for any of you who might want to respond.

West Virginia is rural and poor. In terms of teenage pregnancies among Whites we are second in the country and among the general population we are about fifth. In infant mortality we are seventh-worst in the country. There was a time that our statistics were getting better—there was more money, and our efforts were working. But now it is getting worse again, not only in West Virginia but all over the country.

What is it that a rural woman, in Appalachia or elsewhere, who doesn't have health insurance and who is poor—what does she lack? What services and attention does she not have to help herself, on the one hand; and on the other, what is it that a middle income woman let's say who does have insurance do? Just give me a brief description.

Ms. ROSENBAUM. Yes. First of all, I think it is important to note that, for women who have been lower income all of their lives, prenatal care really shouldn't start at the time that they become pregnant. Many lower income women have grown up in lives of health deprivation and thus enter a pregnancy in reduced health status. They may be suffering even by their early twenties from a host of illnesses and conditions that do not affect upper income women: diabetes, hypertension, other kinds of problems that can complicate a pregnancy.

So, it is important to understand that lower income women are not infrequently beginning a pregnancy in reduced health status.

Second of all, of course during the pregnancy prenatal care is vital both for the outcome of the baby and for the mother's outcome. Something I don't think is well understood in this country is maternal mortality. The numbers are very low, compared to infant mortality, yet maternal mortality rates are shockingly high in the United States. Moreover, one-third is estimated to be preventable. And so we find women who are not getting the prenatal care that would prevent low birth-weight births, they are not getting regular checkups, they are not getting nutritional supplements, they are not getting thorough medical examinations and treatment for, for example, early signs of pre-term labor and other conditions, and they are also not having their own health attended to, which can be fatal to them.

Additionally, and I think this is also particularly shocking, women who are low income and uninsured are to an alarming degree in the United States not having what is called a "risk-appropriate delivery." It has been estimated that our infant mortality rates could be reduced by about 20 percent if women who were at medical risk were being delivered in appropriate facilities.

Now, there are many women who present low risks who can have home births, or birthing center births, or births in a lower level of hospital; but there are a number of women who must, for their own health and that of their infants, be delivered in an appropriate facility. In fact, we had one public health official recently tell us quite explicitly that in her State—this was Kansas—the Regionalized Perinatal System is for insured people. What she meant was that there was no way to get lower-income uninsured pregnant women preregistered for a risk-appropriate delivery at a proper institution; they must show up in emergency labor at any hospital

that will take them in. The transfer of a baby after birth is far more difficult than a predelivery transfer.

And finally is the issue of infant health care. Families who have suffered all of these deprivations during the perinatal period will continue to suffer those deprivations for their babies, as in the case of the Mississippi baby's story that I related. I would add that West Virginia has just in fact enacted the new 1986 Medicaid amendments. The West Virginia Legislature rallied to push them through, and after many close calls they were in fact signed into law. These amendments should more than double, we think, the number of women in the State who are eligible for Medicaid.

Dr. CICCO. I would add to that our observations that infant mortality had been dropping for a number of years, prior to the last few years, is true, but relate it primarily to the fact that technologies in the neonatal intensive care nursery were improving, and our ability to keep a baby who weighs a pounds and a half alive have improved. What had not changed during the time that infant mortality and neonatal mortality was dropping, what had not changed, was the incidence of premature labor and premature birth, which ultimately is the key issue, which is ultimately why other countries do better than the United States—it is that they have lower rates of premature births.

We felt very comfortable because our neonatal and infant mortality was dropping and dropping and dropping, but it was dropping for the wrong reasons; it was not dropping because we were doing a better job in preventing premature births, we were doing a better job keeping those babies alive. And that better job has come at an extremely great cost to the health care system.

Senator ROCKEFELLER. That is the $110,000 that you were talking about?

Dr. CICCO. Right.

Senator ROCKEFELLER. One final point on that: Often, at least in Appalachian rural areas, you get people who are afraid of authority figures. That could mean law enforcement; it could also be a doctor. In other words, people can even believe that if they bring their problems to somebody who might be able to do something about them, their worst expectations will be realized. I remember this very well from my days as a VISTA volunteer in West Virginia. In the community where I was working there were no doctors, and there were no doctors who ever came there or got close to there. You could bring out a medical service—for example, a pap smear—but people would stay away from it because it was medicine. Medicine might judge something is wrong. It is authoritative and frightening, and therefore people stayed away from the service. Now, that could be habit; that could be a habit easily broken. Is that a problem?

Dr. CICCO. I think it is. When Senator Mitchell asked me before whether or not I felt that it was more than just a matter of money, there is no question that it is.

Many of the population that we are talking about are not aware of this being a problem. They are not aware that their baby's chances of dying are greater than in some Third World countries. We need to bring that education in. We need to let them know that in fact the situation does not have to be as it is. And in fact there

are things you can do about it, if in fact we not only provide the prenatal care but educate people that obtaining that prenatal care will improve the outcome of their children.

Senator ROCKEFELLER. So, it is not just making the service available but creating the feeling that the service, if used, is useful.

Dr. CICCO. And setting the service up in such a way that it is a quality service and not one that belittles the patient.

Senator ROCKEFELLER. Thank you.

Thank you, Mr. Chairman.

Senator MITCHELL. Thank you, ladies and Dr. Cicco.

We are pleased to be joined now by our distinguished colleague Senator Weicker of Connecticut.

As the Chairman of the Senate Subcommittee on the Handicapped, and as Chairman of the Senate Appropriations Subcommittee on Labor, Health and Human Services, and Education for six years, Senator Weicker has contributed as much as any person in our nation to the protection of the health of the American people and to children and handicapped and others who face difficult times in our society.

So, we are genuinely honored and pleased to have Senator Weicker here with us, and we look forward to your testimony, Senator.

Senator CHAFEE. Mr. Chairman, could I just say one thing? I think we are fortunate to have Senator Weicker here. As you said, he has been a leader in this field for so many years, and he is a man whose opinions are not masked in any way. You know where Senator Weicker stands on any issue. And on these issues, plus the issues you mentioned, Mr. Chairman, he has been a vigorous and I might say loud voice in the area. I think every American has benefited from his tremendous efforts in this area. So, I want to share in the welcome to Senator Weicker.

Senator MITCHELL. Would you like to welcome Senator Weicker?

Senator ROCKEFELLER. Yes, I think he is a great Senator, too. [Laughter.]

Senator MITCHELL. This is all coming out of your time, Lowell. [Laughter.]

STATEMENT OF HON. LOWELL P. WEICKER, JR., U.S. SENATOR FROM CONNECTICUT

Senator WEICKER. Thank you all very, very much for your very decent and very kind remarks.

Before I get into my testimony, if I can just make one remark, in listening to the distinguished witnesses you have before you, you know there really shouldn't be any mystery as to this matter of increased infant mortality, low birth-weight babies. Everybody thinks we can do this little budget-cutting act around here and there are no consequences to be paid. Well, there have been consequences to be paid, and they have invariably been paid by those who either have no voice at all—the unborn or those just born, or the poor, or whatever have you.

The fact is, when we cut maternal and child health care, and when we cut the community health centers, and these women are arriving in the hospitals in labor and that is the first time a doctor

has ever seen them, there is your problem right there as to low birth-weight babies, infant mortality, and the rest.

As was indicated, the technology certainly has been soaring, and the expertise has been soaring as far as personnel are concerned; but the availability of that prenatal care, that has not been soaring. That has either been level or going down, or non-existent. So that is the type of money which we invest here that has enormous consequences, not just in human terms but in economic terms, because I think you are well aware as to the difference between caring for a regular birth-weight baby and a low birth-weight baby. It is a tremendous disparity as to what the cost is.

I would suggest, for those of us who want to cut down that mortality rate and the low birth-weight rate, that we take a look at those programs which to some degree at least, and a great degree, will accomplish that fact.

I am very upset over the fact, for example, that in my State of Connecticut, which is the wealthiest in the nation, the infant mortality rates in Hartford and New Haven are as bad as they are in many Third World countries—in this wealthiest of all States, in these two most sophisticated of all cities. And that situation exists. It is absolutely intolerable, I think, and it should be to the people of Connecticut as well as the people of this nation.

Mr. Chairman, I thank you and your subcommittee for holding this important hearing today. There is a dire need to provide assistance to families who have children whose illnesses are not only a crisis of health but a catastrophy of family finances.

Last spring I introduced legislation which seeks to address this pressing issue, and I welcome the opportunity today to speak to the problem.

We hear a lot these days about providing catastrophic coverage for senior citizens, and well we should. But we must not forget that a child's illness or injury can be just as debilitating for a family as that of a grandparent. Private insurance and Medicaid do not provide adequate coverage for seriously ill children.

Whether it be the absence of any insurance whatsoever or not enough insurance, or the cost associated with the deductibles, copayments, and the exclusion of some types of care—all these factors add up to overwhelming financial as well as emotional burdens on the families in question. Under the present system, no family is immune. Often young parents have no savings; and, even if they do, those savings are quickly spent, and soon they face a permanent mounting debt in order to provide the care their children need.

I recently learned of a boy in Connecticut who was found to have acute lymphocitic leukemia. When this disease went into remission, bone marrow transplantation was advised. His family discovered the cost would amount to $100,000; and furthermore, most treatment centers require a guarantee that the family be able to pay should insurance fail to cover the expense. In this child's case, the HMO to which he belonged had no provision for bone marrow transplantation.

Consider this family's predicament. They can't say, "Sorry, son, we can't afford it." The only choice they have is overwhelming debt or death.

Take another example, which I didn't include in my remarks, on the other side of the spectrum: My good friend Nick Bonoconti, who has a young son Mark who received a spinal cord injury in a football game, and who has been doing a fantastic job in recuperation. Nick, who is the president of the U.S. Tobacco Company in Greenwich, had insurance—the corporation had insurance. They could afford the unbelievable cost for Mark's care and hopefully for his eventual rehabilitation. What other family could? And Nick himself, being the personality he is, goes out and works on behalf of not only his son but other kids in the same predicament day in and day out, raising money for it. But that is a fortunate situation, from a parent's point of view, as he looks upon his child in that condition.

So whether you are talking about the Nick Bonoconti's of this world or the persons with no names and no money, the situation is the same: It is a terrible tragedy and a very expensive one.

A point I also want to make, because it it not in these written comments of mine, is the fact that when it gets to the business of who has the voice and who doesn't have the voice I understand, as I said before, the necessity for catastrophic health insurance as far as the elderly is concerned. I don't dispute that; that should take place. But you know as well as I do that the reason we are moving on that first is because of the political impetus behind it—they are voters.

This constituency which we are speaking for here has no votes—they have no votes. But it seems to me that we have got the power. If we want to exercise it, we can exercise it on behalf of both those that have the votes and those that don't.

A recent nationwide study determined that parents of leukemic children spend 38 percent of their adjusted gross income on health care for their sick child—38 percent. These out-of-pocket costs amounted to an average of $29,700 per family in 1985.

But it is not just leukemia that is burdening families. Remember the children with cystic fibrosis, cerebral palsy, muscular dystrophy, hemophilia, sickle cell anemia, congenital heart disease, traumatic spinal cord injuries, burns—the list goes on.

Now, under S. 1283, the Medicaid Catastrophic Coverage for Children Act, families become eligible for coverage based on the percentage of their adjusted gross income they spend on medical expenses. All States will be required to adopt this program, guaranteeing that families from Connecticut to California will be on an equal footing. And once the child is covered, a multi-disciplinary care coordination team consisting of family and health professionals will design a plan to suit the child's specific needs.

In addition to the medical and financial problems, a child's serious illness creates other burdens. Health care must be coordinated with the routine activities of the family and the needs of the other children, and the families must learn about community resources and how to deal with the bureaucracies and the special rules relating to reimbursement and eligibility for health and school services. An health care management team must be an integral part of any successful program.

All of us in this room who have studied this issue are aware that data on catastrophically ill children and their families are sorely

lacking. We do know there are 37 million Americans without any health insurance, and that 30 percent of these—30 percent of these—are minors.

As you know, Senator Kennedy and I have introduced the bill relative to mandated health benefits, and I have got to tell you, you ought to see the flak that I am getting on that one.

I don't know how this nation can sit around, while 37 million people, 30 percent of which are kids, have no medical coverage. "It's too expensive." Well, just out of curiosity, how do these people get taken care of now? I will tell you how they get taken care of: By an ad hoc system that is far more expensive than any sort of an organized approach to help kids, because as a nation we are going to take care of them one way or the other, and I think what we are proposing—whether it is this bill that I have before you or the other, and I know I am just talking on this one—if we will direct our efforts into a well-planned effort, believe me it is far less expensive than that which we assume in an ad hoc fashion today.

Mr. Chairman, I have to be on the floor because of the conclusion of the warped bill embodying the War Powers legislation. I would like to include the remainder of my statement for the record.

I want to thank you. I know each one of the gentlemen on the panel here. I know how each one of you, on every one of the issues I have mentioned, has interested themselves in the lives of those who have no voice and no vote. And believe me, you have got my deep respect for that. There is nobody to thank here, but I think among ourselves we know who is doing the job, and I know the three of you are.

Thank you very much.

Senator MITCHELL. Thank you very much, Senator Weicker, for your very impressive and compelling testimony.

Are there any questions by any members of the panel of Senator Weicker? Senator Rockefeller, do you have any questions?

Senator ROCKEFELLER. No.

Senator MITCHELL. Thank you very much, Senator.

Senator WEICKER. Thank you.

Senator MITCHELL. The next panel includes Jerome Paulson, M.D., member of the Council on Government Affairs, The American Academy of Pediatrics; Charles E. Gibbs, M.D., The American College of Obstetricians and Gynecologists, who is from San Antonio, Texas; and Mr. Robert Sweeney, President of The National Association of Children's Hospitals and Related Institutions.

Good morning, gentlemen. Welcome. We look forward to your testimony, and we will begin with Dr. Paulson.

STATEMENT OF JEROME PAULSON, M.D., MEMBER, COUNCIL ON GOVERNMENT AFFAIRS, AMERICAN ACADEMY OF PEDIATRICS, WASHINGTON, DC

Dr. PAULSON. Good morning, Senator. I am Jerome Paulson, a pediatrician and a fellow of the American Academy of Pediatrics. I am here today on behalf of the Academy, selected other pediatric organizations, and multiple groups from the Consortium for Citizens with Developmental Disabilities.

Given our time constraints, I am going to focus my remarks on the issues of catastrophic health insurance for children, the Maternal and Child Health Block Grant, and vaccine compensation legislation.

At the outset, though, I want to underscore that the groups on whose behalf I am appearing strongly support enactment of the Medicaid expansions eloquently described by Sara Rosenbaum. In particular, we urge inclusion of S. 422, Senator Bradley's Infant Mortality Amendments, in its entirety in the budget reconciliation package. For an estimated $65 million, this proposal would potentially aid 79,000 pregnant women and 239,000 children under the age of five in 1988—a relatively small amount of money to provide coverage to some of those who are most in need. We thank Mr. Bradley for crafting this progressive set of amendments, and we thank the rest of the panel for cosponsoring the bill.

The issues surrounding catastrophic health expenses incurred by children and the underlying problem of uninsurance and under-insurance are significant and profound. Although a true solution to these problems will require a thorough and comprehensive examination, there are significant proposals before you which deserve attention, proposals that are consistent with previous Medicaid expansions and which would set the stage for consideration of a more comprehensive catastrophic policy for children.

Of particular note is Senator Chafee's MedAmerica Act of 1987. The proposal addresses some of the major barriers to insurance coverage for persons with disabilities, who are those most often confronted with catastrophic health care costs. We applaud you, Senator Chafee, for your thorough analysis of the policy issues involved and your creative approach to their resolution.

Should MedAmerica prove too ambitious to be enacted in toto, we feel that one component deserves special attention. Persons with pre-existing conditions who have been denied insurance, or those who have exhausted their insurance, should be allowed to purchase Medicaid at a State's option. At a minimum, this concept should be explored on a demonstration basis.

Another proposal, built on the concepts in MedAmerica but more limited and perhaps more feasible, is Senator Durenberger's excellent Medicaid amendments for children with chronic illness and children with disabilities. We thank Senator Durenberger for putting this proposal together, which is unique in that it would allow States to extend Medicaid coverage to children with chronic illness and children with disabilities in families whose income is under 185 percent of poverty. Care and services under the program would be furnished in accordance with an individualized written health care management plan developed under the direction of the designated case-management agency. The plan would emphasize the delivery of services in the least restricted setting, with an emphasis on family-centered community-based services.

The need for this legislation is clear and pressing. An estimated 5 percent of all children under age 18, or 3 million children, suffer from a chronic illness or disability that significantly limits their lives and daily activities. Over 1 million children with serious illness and disability live below or near the poverty level. Several hundred

thousand of this group are completely uninsured, many others underinsured.

Therefore, we strongly urge you to enact S. 1740, the Medicaid Amendments for Chronically Ill and Disabled Children, as part of reconciliation. This legislation is consistent with previous Medicaid expansion, would facilitate the development of a coordinated, comprehensive delivery system at the State level, and would help serve children who are most in need.

As previously noted, a comprehensive solution to these problems is not at hand. In part, this is a result of the lack of a thorough evaluation of the situation. For example, the Maternal and Child Health Block Grant, which is an extremely important program for children, has not been examined through a hearing since its inception in 1981. For these reasons, we urge the committee to hold a series of hearings on children's catastrophic health expenses, children's access to health care, and the ability of the Maternal and Child Health Block Grants, Medicaid, and other child health programs to meet the complex and changing needs of today's children and their families.

For the same reason, we urge enactment of Senator Bentsen's Commission on Children to provide another focus for the review of federal programs for children.

Finally, we urge the committee to adopt a financing mechanism during reconciliation for the Vaccine Compensation Law. Although this important program was passed last year, the law does not become operative until a funding mechanism is established. Specific recommendations will be provided to you pending House action. Until this issue is resolved, vaccine prices will continue to rise, and children will remain at risk for totally preventable diseases.

Thank you.

Senator MITCHELL. Thank you, Dr. Paulson. That is a commendable standard of timing that you made, that other witnesses will be hard-pressed to meet; but we look forward to their effort. [Laughter.]

Senator MITCHELL. Dr. Gibbs, welcome.

STATEMENT OF CHARLES E. GIBBS, M.D., THE AMERICAN COLLEGE OF OBSTETRICIANS AND GYNECOLOGISTS, SAN ANTONIO, TX

Dr. GIBBS. Thank you, sir.

Senator Mitchell, Senator Chafee, this is a new experience for me; I hope you will excuse my nervousness.

I am an obstetrician and gynecologist finishing up 40 years in that work. My credentials include being on Governor White's Task Force on Indigent Health Care which, when it offered its report two years ago, resulted in the enactment and funding of five different pieces of legislation directed at the care of indigent patients in our state.

Maternity care is one of those things in which "you can pay me now, or you can pay me later." If you pay now, in terms of adequate care, you save the later payments in terms of sadness, sorrow, grief, and money.

We have talked a lot about infant mortality, but I think it is important to realize that this accounts for only 60 percent of the deaths. We have not said anything about fetal deaths, and if you are a mother who carried a baby for 40 weeks and delivered a stillbirth, the sadness, the pain, the grief associated with that is just as acute and just as severe as if that baby dies in the nursery on the second day of life.

In preparing our report in Texas, we found that our State encumbers $175 million every year in short and long term costs for the neonate, in terms of neonatal intensive care nursery costs, domicillary costs for handicapped, and extra educational costs. Out of that $175 million encumbered every single year, it appears to me and it appears to our legislature that we could fund improved care.

I would like to define maternity care as preconceptional, prenatal, interpartum, labor and delivery, and an effective follow up for the first year for both mother and baby. And I would like to define medical indigency or medical poverty as that state where a couple, a woman and her husband, a woman needing medical care for the care of her pregnancy and her baby, can't pay for it. Maternity care today has a much broader financial range than it did when I started practice. Then it was a blood pressure cuff, a tape measure, a scale, and chewing her out because she gained too much weight. Now it is ultrasound, amniocentesis, all sorts of laboratory work, and consulting with nutritionists and psychologists. We have to supply, when it is appropriate, those kinds of services.

We have problems in insufficient prenatal care, and we also have problems in coupling prenatal care with labor and delivery. It is very frequent that we find a community that offers prenatal care through a public health institution but makes no provision for an appropriate environment for the birth. And we are having real difficulty in accessing physicians and hospitals for patients who are uninsured or who are receiving Medicaid benefits.

In Texas, Medicaid plays a role in the care of about 10 percent of all births, or about 30 percent of those patients with incomes under 100 percent of poverty. The MCH Block Grant plays a real role in providing prenatal care but offers very little support in terms of accessing an appropriate environment for birth.

The American College of Obstetricians and Gynecologists supports S. 422, the expansion of Medicaid. We support demonstration programs to allow us to figure out how best to gain access for poor patients to hospitals and doctors. We support the expansion of the MCH Block Grant. And we certainly support the maintenance of the existing Medicaid match for family planning services. An editorial I wrote over 10 years ago emphasized the point that family planning is truly a preventive health service. And we would hope for active encouragement for the States to enact the 1986 OBRA options for Medicaid eligibility and presumptive eligibility.

Again, I am honored to be here, and I appreciate your listening to my observations.

Senator MITCHELL. Thank you very much, Dr. Gibbs.

Mr. Sweeney?

STATEMENT OF ROBERT H. SWEENEY, PRESIDENT, NATIONAL ASSOCIATION OF CHILDREN'S HOSPITALS AND RELATED INSTITUTIONS, ALEXANDRIA, VA

Mr. SWEENEY. Thank you, Senator Mitchell.

I am pleased to be here representing the Children's Hospitals of this country. We have submitted a full statement, and I will even summarize the summary that I had prepared.

We come here with the basic premise that America can afford its children, and we would urge the committee to consider that premise for its modus operandi for its work in the future.

Children's Hospitals feel a certain franchise to speak to the needs of children; we care for one of every 12 children hospitalized in the country, and about one-third of our patient population are either Medicaid patients or patients who have no ability to pay.

We believe that the problem of financing children's health care demands a multi-faceted approach: It must ensure access to preventive health care, particularly for pregnant women and young children; access to public and private health insurance, to cover a broad range of acute and chronic health care needs; and government insurance as a last resort to protect both insured and uninsured families from costs that exceed their insurance and jeopardize their financial stability. It is interesting that we do that in the instance of flood insurance and home mortgages, but we haven't decided to back up our families for the catastrophic equivalent of a flood in the health care of their children.

The legislative leadership of several members of this committee, including Senators Bentsen, Bradley, Chafee, Durenberger, and others, demonstrates a keen awareness of the breadth of legislation required to deal with the health care needs of children.

NACHRI supports Senator Bradley's Medicaid infant mortality amendments, Senator Chafee's catastrophic bill and MedAmerica, and Senator Durenberger's new chronic care proposal.

We have worked especially closely with a coalition of organizations supporting Senator Chafee's catastrophic bill that would insure families against the most extreme catastrophic cases, those where expenses exceed $50,000 and out-of-pocket obligation of over $10,000 or 10% of A.G.I.

Together, these four bills represent a comprehensive package of initiatives to contain the problems of children's health care coverage and fill in the gaps. But we are also acutely aware of the budgetary pressures on the committee as it assesses these measures. Congress has adopted a budget resolution that simply will not accommodate the costs of all of them. Therefore, we make the following recommendations for the committee's consideration when it undertakes the markup of the Reconciliation Bill:

First, adopt the Medicaid Infant Mortality Amendments in full. They are fully covered by the budget resolution.

Second, lay the groundwork for enacting within the next year legislation to cover the very high-cost catastrophic cases targeted by S. 1537. The committee can do this by using the Reconciliation Bill to direct either GAO or OTA to produce studies within the next six months that document the extent of the children's catastrophic problems.

Third, adopt Senator Bentsen's proposal for the establishment of a Commission on Children, to get a broad overview of the needs of the children of this nation.

Fourth, if additional funding should prove to be available under the 302(b) allocation, the committee should look first to expand the mandates for additional Medicaid coverage under S. 422 for pregnant women and children. The committee also should consider the possibility of phasing in Medicaid buy-ins, perhaps through a demonstration targeting the chronically ill and disabled.

Now, these are the immediate steps that can be taken.

We do think, over the longer term, the committee would do well to take a comprehensive look at Medicaid and determine whether Medicaid is meeting truly the needs of American mothers and children.

We talk about Medicaid buy-ins, Medicaid buy-ins would be highly desirable in a State that has a good comprehensive Medicaid program; but if we tell people with an income up to 200 percent of poverty in the State of Alabama, "We have now provided you a Medicaid buy-in," which allows them to buy 12 days of hospital care and 12 or 14 ambulatory care visits during the year for their child, we really haven't provided very much. We must address the fact that it is time we looked at America's children—not Alabama's children, not Mississippi's or Minnesota's—America's children.

Thank you, Mr. Chairman.

Senator MITCHELL. Thank you very much, Mr. Sweeney.

Dr. Gibbs, you said at the outset that you were nervous because you hadn't done this before. I want to assure you that you did very well and provided very informative testimony to the committee. Your experience is the thing that of course gives weight and force to your views, and I want to assure you that we will consider those and the views of others very carefully.

Dr. GIBBS. Thank you.

Senator MITCHELL. I wanted to ask you a question about the problem of babies delivered under Medicaid. In Maine, my home State, deliveries of babies under Medicaid by obstetricians is at an all time low, and I am concerned about access to quality health care for all, including those Americans who live in rural areas. Our experience in our State, where we have a large number of persons living in rural areas, is that they tend to have lower incomes and less opportunities available to them in some respects. Do you find, in your experience, that this is a problem that is particular to rural areas? That the availability is less there than in others? Or is this something that is unusual just in our State or region?

Dr. GIBBS. No, sir, that's not, I'm sure, unique to Maine. It is a real problem. One of the things I have been doing for the last year and a half is going around to rural Texas trying to recruit physicians into our local Texas supplement to Medicaid.

We have relied for years, of course, on family physicians to do the bulk of obstetrics in rural Texas, and the professional liability issue has about wiped out that resource. It has been a major problem. The premiums of a friend of mine practicing in Northwest Texas went from $1500 to $6,000 a year, and he could drop it back down to $1500 if he just didn't do the 30 or 40 births a year that he did. That is a significant problem in accessing care, and when you

access a doctor and obtain a doctor's care for a maternity patient in rural Texas, you access the hospital. But if you don't access the doctor, if you don't recruit him or her, then you don't have the hospital—except for, as all the hospital administrators know, the patient who comes in at six centimeters. They can't send them home; they are going to deliver them—someone is going to catch that baby. A terrible kind of obstetrics.

So, to answer your question, yes, sir, it is a problem. It is really a severe problem in rural America.

We have 254 counties. Fifty-one counties supply a public hospital, and four of those county hospitals don't supply an obstetrical service. That is not where the preponderance of deliveries are, it is only about 20 percent of the births in the State; but it is a lot of area.

Senator MITCHELL. Do either of you other gentlemen care to comment on that subject? Dr. Paulson?

Dr. PAULSON. Senator, I have practiced in Baltimore, Maryland, in Cleveland, Ohio, and now the Greater Washington Area, none of which constitute rural areas, and my practice has been in pediatrics. All of my practice has been at either Children's Hospitals or at hospital-based primary care pediatric practices. However, the problems that you allude to in regard to access exist in urban areas as well, and they exist for pediatric patients as well as for obstetric patients. In none of the areas where I have practiced have large numbers of pediatricians or family practitioners been available to provide children on Medicaid with health care, for reimbursement makes it virtually impossible. And therefore, the care of those children generally does fall on to the primary care practices at the Children's Hospitals or the other hospitals in the community.

Senator MITCHELL. Mr. Sweeney?

Mr. SWEENEY. There is another tired old canard we use in the health care delivery system that "the poor practice episodic health care; when they are sick they come for it, and when they are well they don't do anything to preserve their wellness." And that, like most old canards, is probably not very accurate.

I think our hospitals, which are part of our society and societal instruments, both the voluntary ones and the public ones, have taught the poor that they dare not show up unless they have a real need. And we have done that for generations. It has been inculcated in people, and that is the way they now feel you obtain health care services.

Senator Rockefeller and others mentioned earlier the question of the need for education. It is a crying need. It is very frustrating to these physicians, I know, to see a youngster brought to them with a serious ear infection when, with early intervention, the child could have been treated for just a mild upper respiratory sort of condition.

But we have trained people that way because our society has begrudged them the resources that we have dedicated to their care. We need to turn that around. I reiterate: This great Nation can afford its children. If it can't, then there is not a great deal of hope for it.

Senator MITCHELL. Thank you, Mr. Sweeney.

Senator Chafee?

Senator CHAFEE. I thank you, Mr. Chairman.

I would like to ask a question of Mr. Sweeney and Dr. Paulson.

As you agree that we should include pieces of the MedAmerica proposal in reconciliation, perhaps we could include the parts that provide that those who have exhausted their private insurance, or those who cannot get private insurance because of some pre-existing condition of some nature, under the MedAmerica proposal while these folks would still have to pay the full premium of Medicaid. Do you think that would get us somewhere, if we put those in Reconciliation? I don't think those would be a financial drain, but it would get us started on some of these MedAmerica proposals.

What do you think of that, Mr. Sweeney?

Mr. SWEENEY. I think, short-term, Senator, it is not only desirable, but it is probably very necessary. As you know, when we were working on our catastrophic proposal and presented some data to you, we showed you the extent of the fiscal damage and the emotional damage that were being done to families by extremely high-cost pediatric cases. One of the figures that we were able to document was that 97 percent of the newborns are routine in the cost of their care. Three percent of newborns in this country use 47 percent of the resources employed in the care of newborn.

Senator CHAFEE. I think I would like you to repeat that, if you might. That is an astonishing statistic. Could you say that one again?

Mr. SWEENEY. Three percent of the newborns in this country use up 47 percent of the resources devoted to all newborn care. And at the pinnacle, one-quarter of one percent of newborn infants use 18 percent of the resources employed in the care of newborns.

Now, these are families, generally young—that seems to be the baby-bearing age—fragile financially, getting started, making mortgage payments, doing the things young families do. And an institution such as the one I represent can come to those families and say, "Well, here is your baby, and here is your bill," and it is $100,000 or $200,000 or $300,000. Services were rendered, and the best available, but the fact remains that the family is just confronted with an absolute financial catastrophy. There are only about 10,000 of those families.

The news was filled last night with the tragedy that six people were killed in California in an earthquake—and tragic it was—and we talk about the devastation and the loss of property values from that earthquake; but there are 10,000 faceless and nameless young families out there in the country each year confronted with this kind of expense. And we can save those 10,000 people and keep them on the strong side of the economy with the kind of help you propose with MedAmerica. But we must recognize the limitation of Medicaid buy-ins—that families in some States will benefit far better than families in other States because of the basic structure of the State Medicaid Program.

Senator CHAFEE. Let me ask you another question. It is my belief that if a side benefit of MedAmerica, the expansion of Medicaid, would involve not necessarily the totally poor families—in other words, this proposal I just talked to you about, where they can get it if they have exhausted their private insurance or else they have a pre-existing condition—it is my belief that there is a side benefit for getting those folks involved in Medicaid, because those folks

are of the educational background and are in positions in the community that they can call attention to what is happening in Medicaid.

I think everything that has been said here today about these users of Medicaid in most instances are the poor, the ones whose voices are not heard, they are not voters, not able to get up there and scream to the world about what is going on.

Mr. SWEENEY. Well, I think you will find that the application procedure in many States would be streamlined if you were dealing with young families who perchance were college-educated and had a little more degree of sophistication about the way you go about things in life, and they were faced with one of these $100,000 babies. I think the State officials might respond to that in a positive way.

Senator CHAFEE. What do you think, Dr. Paulson?

Dr. PAULSON. Senator Chafee, I think that would be very beneficial. As a pediatrician, I don't deal very much with the Medicare program; but one of the principles that has been held in the Medicare program since its inception is that it involve people of all socioeconomic levels, and one of the reasons for that—and I think one of the benefits that has accrued to the Medicare program because of that—has been the maintenance of a higher level of quality of services than might otherwise have been available if Medicare had solely been a program for the poor elderly, as Medicaid has been a program primarily for the poor.

Let me also get back to the first question that you raised about allowing people with pre-existing conditions or who have exhausted their insurance to buy in to Medicaid. I think that would be a good place to start.

We know that people with chronic health conditions require a higher number of physician visits every year, and we know that people without access to insurance do not make those increased number of visits that their condition requires. So, providing them with the insurance would provide them with the back-up to allow them to make the visits they need, to maintain their health at an acceptable level, and perhaps not generate as high expenses as they would with no access at all.

Senator CHAFEE. One final question to Dr. Gibbs, if I might, Mr. Chairman, and that is: I think the point you made about the insurance—I believe that these family physicians that you have encountered in Northwest Texas that say they are not doing the obstetrics and deliveries any longer because of the insurance situation, and then they are not delivering so the patient cannot get into the hospital—it is a terrible cycle. But we are seeing that in my State, which is hardly rural. In some of the non-urban areas, "suburban" if you want to call it that, we are finding doctors who just say, "Forget it." They are now 60, maybe and that is just one grief they don't have to put up with. So they are giving up their obstretrics and are continuing the pediatric work, and we are in a terrible bind in some of our hospitals. What is the solution?

Dr. GIBBS. I am glad you asked that question. [Laughter.]

Senator CHAFEE. And it must be true in your State, too, Mr. Chairman—isn't it?—that we don't have obstetricians.

Senator MITCHELL. Yes.

Dr. GIBBS. The worst thing that has happened as a result of the professional liability issue is that it has separated the doctor from what ought to be his first concern, and that is the patient. What we need to do is to separate the issue of financial compensation and support for the patient who has a bad outcome in obstetrics—that is, a dead baby or a damaged baby—from the issue of incompetent doctors. We mustn't look to the slick lawyer, the patient who gets "in good hands," to recover funds. We mustn't look to that system. We have got to have a system—please excuse the sermonic tone; this is a big issue—we have to have a system where the outcome is dealt with, and the doctor is an advocate for the patient.

If the youngster needs neurologic rehabilitation, the mother needs help with grief in the case of loss, that ought to be dealt with in a system which doesn't depend upon legal skills but depends upon the need.

On the other hand, we must have more guts as physicians, and you must protect us in terms of lawsuits, to deal with the people in our professions who need being dealt with. All of malpractice is not bad doctors; in most of malpractice, the issue is that people need compensation, they need help to deal with the results of a bad outcome, and the only way to get it is to sue somebody. Well, we need to separate that. We need to provide the help, irrespective of the cause of the bad outcome, and then where a bad outcome is due to inadequate care because society doesn't provide it, or inadequate care because of professional or hospital neglect or poor practice, we have to deal with that as a separate issue. And I think if we could get to that point, then we would not have doctors losing what is really the most pleasant part of obstetrics and gynecology, delivering babies.

Doctors are dropping out not at age 60 but dropping at age 38 and 40. So I think that is the solution, and I believe it would work.

Senator CHAFEE. Well, thank you very much.

I want to thank all of you for the push you have given on this proposal I have, on MedAmerica. I am absolutely convinced that the expansion of the Medicaid Program, as mentioned before by Ms. Rosenbaum—or was it Dr. Cicco?—is that that is the program we have got out there, Medicaid. And what we are trying to do is expand it so that it takes care of these people who just are not receiving the care now.

Thank you very much.

Senator MITCHELL. Thank you, Senator Chafee, and thank you, gentlemen. I appreciate your testimony.

The final panel includes Dr. William Hollinshead, President of the Association of Maternal and Child Health Programs, and Commissioner of the National Commission to Prevent Infant Mortality; and Ms. Barbara Shipnuck, County Supervisor, Monterey County, California, testifying on behalf of the National Association of Counties.

Good morning. Welcome to you, Dr. Hollinshead; we will begin with you, and we look forward to your testimony.

STATEMENT OF WILLIAM H. HOLLINSHEAD III, M.D., M.P.H., PRESIDENT, ASSOCIATION OF MATERNAL AND CHILD HEALTH PROGRAMS, AND COMMISSIONER, NATIONAL COMMISSION TO PREVENT INFANT MORTALITY, PROVIDENCE, RI

Dr. HOLLINSHEAD. Thank you, Mr. Chairman.

Like Dr. Gibbs, I am a little nervous with the honor and the decor. I will trim my testimony down substantially.

Senator MITCHELL. You are much less nervous than any of us would be examining a patient, Doctor. Look at it that way.

Dr. HOLLINSHEAD. Like many of my predecessors, I am also a pediatrician, although now I am working largely on the wholesale side of the trade.

The Association of Maternal and Child Health Programs is pleased to give testimony on the catastrophic care and the Medicaid and the infant mortality initiatives now before the committee. Our members are directors of State maternal and child health programs and of programs for children with special health care needs.

To begin, let me briefly describe the current situation from the perspective of these State health programs. Simply stated, America is not the safest or healthiest place to be born or brought up in the eighties, for many of the reasons that have already been highlighted.

In our work in the 50 States, we see that health care coverage is weakest for young families with children, that most low income families are still not eligible for Medicaid, and many eligible families are not enrolled, and that insurance coverage does not include many of the services that seem to make the most difference to good outcomes—services like care coordination, education, family support, respite, home care, and a number of others.

Quality of care is sometimes in question, partly because current reimbursement levels do not meet costs, and especially so for preventive services.

I will skip over to a couple of specific recommendations:

We want very strongly to speak in support of care management and catastrophic health care provisions. We have reviewed most closely and worked on those in S. 1537, and we believe we want to make special emphasis on the care management components for any child with anticipated medical expenses exceeding $5,000, since that will be a very important contribution to health and development of these children, in part because it is designed to assist directly their families, who actually turn out to be the primary care givers over the long haul, for these families.

They also support strongly S. 422, the Medicaid Infant Mortality Amendments, and the provisions of the MedAmerica Act introduced by Mr. Chafee.

In summary, I would like to simply note that we wish to assure the committee that Maternal and Child Health Directors will observe four strong public health principles in implementing these reforms at the State level:

First, we believe there must be a conscious investment in outreach and education to the target families, for many of the historic reasons you have heard highlighted.

Second, we intend to continue to work with our colleagues in the Academy and the College and many others, to be sure that good standards of care are enforced in these programs. The issue of the quality of the service is an important one.

Third, we believe the public and the Congress deserve a careful accounting on these initiatives and will work strongly to evaluate these programs promptly and candidly, exercising our mandate to evaluate the health status of entire populations of families and children, not just those covered by specific programs.

Fourth, we know from many years of operating programs, especially for families caring for disabled or handicapped children, that care coordination is a critical element for families with special-needs kids, and it has proven equally important in recent years to assure good prenatal care for high-risk mothers. We believe that care coordination must be done for the sake of better care and better outcomes, not just for short-term cost containment. Title V agencies consider care coordination one of their most important responsibilities.

And as a final aside, in partial response to an observation that you made, Senator Mitchell, the Title V Block Grant Program has a multiple mandate, as you know, to work with all children, to support preventive programs and services for seriously ill and disabled children as well.

There is at times a sense of competition between the services that serve the few with severe problems, disabilities, enormous families needs—the kinds of tragedies that Mr. Sweeney has outlined—and the needs of the voiceless majority that Senator Weicker spoke most strongly for. I think all of us who have worked with that competition for many years see it as an inhumane and unnecessary sense of competition, that a society such as ours must be aware of the needs of both of those groups and must respond in a balanced way to both groups, just as we must deal with the old and the young in an evenhanded way.

Thank you for the opportunity to testify.

Senator MITCHELL. Thank you very much, Doctor.

Ms. Shipnuck?

STATEMENT OF BARBARA SHIPNUCK, COUNTY SUPERVISOR, MONTEREY COUNTY, CALIFORNIA, TESTIFYING ON BEHALF OF THE NATIONAL ASSOCIATION OF COUNTIES

Ms. SHIPNUCK. Thank you, Mr. Chairman, and Senator Chafee. The National Association of Counties is very pleased to be able to present testimony this morning.

Counties provide an essential base for local level program effectiveness. We have the administrative and political processes that allow us to respond to local needs.

The counties in this country run nearly 1600 county health departments which fund and directly provide health care services. In 13 States, counties contribute directly to the States' Medicaid match for federal dollars. Counties are direct recipients, through the State, of Federal Maternal and Child Health Block Grants, and these funds are used in two basic ways: to directly support service provision, and for programs to meet special health care needs.

Counties also participate directly in other State programs for maternal and child health services that offer protection for the high costs of children's medical care.

When the idea of expanding Medicaid eligibility was first being discussed, counties came forward to support that proposal, even though we realized that we might run the risk of running counter to some of the desires of our own States, and even though we recognized that in 13 of those States counties would bear an additional share of the cost for this additional eligibility. For instance, in Minnesota, counties bear 10 percent of the State's match for Medicaid funds; and so, in the phase-in year of expanded Medicaid eligibility, counties will spend an additional $400,000 of county general fund money.

One of the reasons that we recognize the need for this is that we recognize that a dollar spent on prenatal care will save us money in both acute care and catastrophic costs. And so in Monterey County, California, which I represent, one case in the County cost us $170,000 for intensive neonatal care for one infant—and that was full, direct, County General Fund cost.

Therefore, counties would be supportive of Senator Bradley's proposal to extend eligibility to 185 percent of the federal poverty level, because this would cover more of the needy population, more of the near-poor, and certainly more of the uninsured.

We are also very supportive of and look forward to working with Senator Chafee on his proposal, because a stop-loss provision and coverage for the first year of life would be something that would be very important for counties in our delivery of health care to this population.

Unfortunately, I need to report that California's Governor just recently vetoed a bill to adopt optional expanded Medicaid eligibility levels beyond those we already have, and this is particularly troublesome to me, as I represent Monterey County. We have a population of only 310,000, yet we run a $340,000 prenatal care program—clear evidence of great need for these services in our county.

You might be interested to know that Monterey County has the second-highest rate of illegal aliens in the State of California, next to Los Angeles County. We also have a higher than State average of pregnant teens. Therefore, these two tremendously high-risk populations create a burden on us for the provision of prenatal care—one that we recognize and accept, because we realize the tremendous need. And our Board, in our recent budget deliberations, added $100,000 to start a specific program for pregnant teens, above and beyond this $340,000 we are already using to fund prenatal care services.

The area of catastrophic cost protection: Let me just say that there can be no greater joy than to use our advanced medical technology to cure disease and save the life of a child, nor any greater tragedy than to be helpless and unable to respond because of the high cost of such care.

Hard choices underlie the reality of the high costs of intensive medical care. Numerous States have additional health care programs for children that offer valuable lessons at the national level. Originally these programs were focused on cure for crippled or

handicapped children, but they have evolved, to some extent, into health care assurance programs.

Counties participate in the funding for these programs to varying degrees. This ranges in North Carolina from no county match to a 50-percent share for a program in New York State. In some States the services are available only to the lower-income families, but in all States that we contacted there are limits on overall payments—even though in all cases there is also strong political support to keep the list of approved procedures apace with developments in medical treatment and technology, usually the most expensive.

Montana's program has a $15,000 cap per child; California's program requires a 25 percent match, county by county, to participate in a program currently funded at the State level at $70 million.

I would like to just close by indicating that we are very anxious to participate in the development of health care legislation for this nation's children. This issue is an extremely difficult one, and we look forward to participating in discussions on it as the subcommittee continues its deliberations, and we anticipate children's health will be included as part of Senator Bentsen's agenda for the coming Year of the Child.

We look forward to playing an active role with you and stand ready to help in any way we can.

Thank you.

Senator MITCHELL. Thank you very much.

I will have to leave in just a few moments to attend another meeting. I wanted to thank you and Dr. Hollinshead. Senator Chafee will conclude the meeting following his questioning. We look forward to working with you in the future in this important area. Thank you.

Senator Chafee?

Senator CHAFEE. Thank you, Mr. Chairman.

I want to say to Ms. Shipnuck that the figures she gave about her county and the illegal alien situation certainly must raise extraordinary problems, because it is hard enough to get many people to come in to get the required care, particularly those with low education, as has been testified hereto this morning; but when you add to that an element that the people are scared to death that they might be discovered, you have practically an impossible situation. So, I suppose that there must be infant deaths that you don't even know about and maternal deaths that you don't even know about.

Ms. SHIPNUCK. I suspect you are very correct, Senator. We know that in California and also in Texas we have counties that are working very actively with the border provinces in Mexico to try and make sure that there are some provisions of care, to hopefully prevent some of that.

We do find at our county hospital that we have numbers of women who show up having had no prenatal care. Now, you heard discussions from previous panels about late prenatal care; we find people coming in for exactly the reason you state, with no prenatal care.

Now, the new immigration law indicates that some money will be available for health care. We are concerned that that will not nearly meet the tip of the iceberg in terms of the numbers that are

involved, because it is not only the border States with Mexico that have this problem; we have the Southeast Asian refugees, we have persons in the Midwest that are working in the garment industry and other industries. I think we are going to have to monitor that very carefully, because those can be very costly individual cases.

Senator CHAFEE. Dr. Hollinshead, first of all I want to say how nice it is to see you again, and we appreciate the wonderful job you are doing in Rhode Island. But let me ask you a question.

In Rhode Island you are working with certainly a relatively small unit. You have a microcosm, it seems to me, of all the problems that Ms. Shipnuck has on a larger scale—we must have our share of illegal aliens; we certainly have a substantial immigrant population, with language barriers, of the Southeast Asians. Percentagewise, Rhode Island has one of the highest Southeast Asian populations.

With all those situations, and with the extraordinary effort that you and the Governor and the State Legislature have made, do you think we can get on top of this problem? This problem being proper prenatal care for 100 percent of those requiring it? I know that 100 percent is everybody, but I am just curious—how close?

You have the resources, I believe, or close to it. If the resources are provided, can the job be done? Thus, bring down the statistics that Dr. Cicco mentioned—perhaps you were here when he said he thought that that seven percent of the baby population that was born with low birth-weight could be cut in half. How are we doing?

Dr. HOLLINSHEAD. We are doing better, Senator. Rhode Island is a special opportunity to explore these questions, because it is small, and because, as you know better than I, everyone knows everyone and the connections are there if you can learn how to use them.

I am enough of a statistician never to promise 100 percent of anything to anyone; but I think, with some of the expansions that have occurred, taking full advantage of the Medicaid expansions of the last couple of years, and now with an add-on program like many other States that carries prenatal coverage up to 185 percent of poverty, they have a very good shot at it. But it will not happen overnight. It will take us some years, minimum, for the reasons that I think Mr. Rockefeller and several others pointed out: that the hardest to reach patients and families, including some of those with cultural barriers in extreme poverty, it is not just a financial access problem—it is an education problem, it is a suspicion problem. The illegal alien will not come smoothly and quickly to care, necessarily, just because we now have a means to reimburse for some of those bills.

We need to reach out. We need to keep those networks of communication and education going, in some instances for as much as a generation before we will see the full effects.

But I think it has come down. Our statistics, as you know, in the last couple of years have looked better; we are finally looking good among the New England States, rather than bad. And that is partly as a result of some of these program efforts.

Senator CHAFEE. Education is constantly mentioned both in Senator Rockefeller's State and Senator Mitchell's State. He was talking about rural poverty and the educational barriers or fears that are not overcome. But it seems to me that rural situations are dif-

ferent than they were once upon a time, in that now everybody watches television. I don't care whether they are in the most northern part of Aroostook County, Maine, or they are in Hopkinton, Rhode Island, they watch television. Is there any way of reaching these people through the educational programs that the television might provide?

Dr. HOLLINSHEAD. We believe there is. And in the full testimony, we suggested that one of the four principal standards include a conscious investment in outreach education and marketing. Perhaps I should have left in that third word "marketing"—it is in the text. And as you may be aware, in some of the expansions of prenatal coverage particularly, in our State, we, with the new so-called "Right Start" program, plus the Medicaid agency have consciously set aside resources to organize and sponsor new kinds of marketing, including television.

Even with the kinds of resources that we put aside, you can't buy much television, though. So it needs to be a private/public sector effort. I think it is possible, and we are definitely working on it, though.

Senator CHAFEE. I want to thank you for your endorsement of the MedAmerica legislation, the catastrophic health programs for the children. Both of these programs are going to come about some day, but what we want to do is have them come about earlier, and I would appreciate the support of you and any other witnesses in convincing my fellow members of the Finance Committee that that is the way we ought to go. I think the expansion of the Medicaid program is the right way to proceed.

So thank you very much. And if you know other members of the Committee, let them know of your concerns. We appreciate both of you coming.

Dr. HOLLINSHEAD. Thank you.

Senator CHAFEE. That concludes the hearing.

[Whereupon, at 12:23 p.m., the hearing was concluded.]

[By direction of the chairman the following communications were made a part of the hearing record:]

APPENDIX

IMPROVING ACCESS TO HEALTH CARE AND ASSURING CATASTROPHIC PROTECTION FOR CHILDREN

Karen Davis

The Johns Hopkins University

Thank you, Mr. Chairman, for this opportunity to appear before you today to discuss the health of children in our nation. Recent improvements in Medicaid coverage are helping many mothers and children from our poorest families receive needed health care services. Employers provide health insurance coverage to many children of working families. Yet, two major problems remain. First, millions of low-income infants and children remain uncovered by Medicaid and face major barriers to the receipt of needed health care services. Second, uncovered expenses of chronically ill children can inflict serious financial hardship on families.

Today, I would like to discuss these two major problems and offer some short-term and longer-term policy actions to improve access to basic health care for poor children and coverage of catastrophic expenses for all children.

I. The Health of Low-Income Children

Over the years, the United States has made significant strides in improving the health status of mothers and children. Much of this improvement can be attributed to better nutrition, sanitation, and general living conditions as well as increased access to more effective medical care. Infant mortality, one of the most easily measured indicators of health status, has steadily improved over the past decades. In 1965, 25 infants died in the first year of life for every 1,000 babies born. Today, that rate has been cut by more than half to less than 11 deaths per 1,000 births. Much of this progress directly parallels efforts to expand financial access to health care under Medicaid and to improve provision of care under the maternal and child health programs.

However, despite these gains, we remain a nation of contrasts. As the life span of the average American increases, some infants continue to die within the first year of life at inordinately high rates. As we develop increasingly sophisticated medical technologies, many children fail to receive the most basic preventive services. As we debate ways to contain health care costs, millions of children and pregnant women lack adequate financial resources to purchase care.

Health care received during pregnancy and early childhood influences the child's health throughout life. Early prenatal care is essential so that maternal conditions such as hypertension, diabetes, and iron deficiency anemia can be diagnosed early and brought under control. Without such intervention, premature births with resultant mortality or physical and mentally handicapping conditions will occur with high frequency. Adequate medical care in the first year of life is also important to provide prompt medical attention for gastrointestinal, respiratory, or other disorders that can be life threatening for vulnerable infants.

Throughout childhood, low income youths continue to face health problems, some of which may result from inadequate prenatal and infancy care. Poor children are more likely than nonpoor children to suffer from low birth weight, congenital infection, iron deficiency anemia, lead poisoning, hearing deficiencies, functionally poor vision, and a host of other health problems amenable to medical intervention. Poor children are more likely to become ill, more likely to suffer adverse consequences from illness, and more likely to die than are other children.

The National Health and Nutrition Examination Survey shows the proportion of children with significant abnormal findings on examination increases as family income decreases. Children who are poor are 75 percent more likely to be admitted to a hospital in a given year and when admitted, stay twice as long as nonpoor

children. These medical limitations also affect other aspects of poor children's lives. Poor children have 40 percent more days lost from school than children in non-poor households.

Medicaid has been instrumental in improving access to care for millions of poor and near poor children and mothers. In 1984, 9 million children and 800,000 pregnant women received needed health care services as a result of Medicaid coverage. Through Medicaid, more of the poor receive medical care early in pregnancy. In 1963 prior to enactment of Medicaid, only 58 percent of poor women received care early in pregnancy. By 1970, 71 percent of poor women received early prenatal care.

Poor children, particularly those not eligible for Medicaid, still receive less care than nonpoor children. Sick day for sick day, poor children have fewer medical visits, but poor children with Medicaid coverage are better off than those without.

Nearly 6 million children in families with incomes below the poverty level are without Medicaid coverage. Only half of poor children are covered by Medicaid. Of these uncovered poor children, 2 million live in families with incomes below 50 percent of the poverty level. These gaps in coverage occur largely because state income standards for program eligibility are generally far below the poverty level.

Cutbacks in federal financial support for Medicaid in 1981 and reduction in coverage of the poor under AFDC have resulted in a loss of Medicaid coverage for many poor children and pregnant women. The rapid rise in poverty among children in the early 1980s made this cutback in federal support particularly ill-timed. The gap between children in poverty and children covered by Medicaid widened markedly.

It is particularly gratifying, therefore, that the Congress has taken steps in recent years to expand Medicaid coverage for poor children and pregnant women. In the Deficit Reduction Act of 1984, Congress required states to cover all children up to age

5 who met state welfare standards, with coverage phased in beginning with infants born after October 1, 1983. States were also required to cover all pregnant women in families with an unemployed parent who met state welfare standards. In the 1985 Consolidated Omnibus Budget Reconciliation Act, Congress required states to extend Medicaid coverage to all pregnant women under state income standards and permitted states to accelerate coverage of children up to age five.

In the 1986 Omnibus Budget Reconciliation Act, Congress gave states the option to extend coverage to all pregnant women and young children with incomes up to the federal poverty level. Currently, 14 states offer Medicaid eligibility to pregnant women and infants with incomes up to 100 percent of the federal poverty level, and three additional states will have tied eligibility to a percent of the federal poverty level (50%, 75%, and 90%). These are important steps to close the gaps in Medicaid coverage that are so important to assuring access to health care services for this especially vulnerable group of our nation's population.

II. The Financial Burden of Catastrophic Illness Among Children

While access to preventive health services and basic health care can be a serious problem for poor children, catastrophic illness among children can pose a major financial problem for nearly all families. Approximately 12 percent of American children are affected by some physical or mental impairment although the problems are of widely differing severity and etiology. About 4 percent of children are so disabled that they are unable to participate fully in childhood activities.

Asthma is the most frequent cause of functional disability among children, but chronically ill children suffer from a broad range of conditions, including diabetes, leukemia, sickle cell anemia, cystic fibrosis, hemophilia, spina bifida, congenital anomalies, and in recent years AIDS. Children with chronic illnesses such as arthritis, rheumatism, and diabetes report rates of activity limitation of 22 to 25 percent.

Recurring medical expenses are a major burden for the 2.2 million families with seriously impaired children, compounding the strain and stress of coping with the disabling condition itself. Children with chronic disabilities often need medical, physical, and social services; hospital and ambulatory care as part of special therapies; family support services; physical, speech, and occupational therapy; and psychiatric counseling.

Children with chronic illness use more physician services and are hospitalized more often than other children. Severely impaired children have, on average, 21.8 physician visits per year compared to 9.5 visits per year for less severely impaired children with functional limitations and 4 visits per year for children without chronic health problems. Hospital discharge rates for severely impaired children are 1,677 per 1000 compared to 256 per 1000 for children with functional limitations and 58 per 1000 for non-disabled children. When hospitalized, functionally limited children have an average length of stay that is twice that of other children.

The cost for this care is significant and the expenses are not one-time expenditures; they recur year after year and frequently increase as the condition becomes more disabling. In 1982, annual hospital expenditures for a severely impaired child ranged from $5000 to $10,500 compared to annual expenditures of $75 to $150 per non-disabled child. Similarly, the average physician bill for a severely impaired child was $600 per year, almost six times that of other children. It is not unusual for the most severely impaired children to incur annual expenses for health care in excess of $10,000.

Ten percent of the children with functional limitations have no insurance coverage from Medicaid or private plans. Lack of insurance is a financial burden for any family with a child with large medical expenses, but a true financial catastrophe for low-income families. Almost 20 percent of disabled children from families with incomes below the poverty level are uninsured.

Chronically ill children may obtain private health insurance from a parent's employer. Only 55 percent of all chronically ill children, however, are covered by group insurance compared to 76 percent of all children.

The common assumption that private health insurance will cover most expenses a family would face falls short in the case of families with a chronically ill child. Being insured does not mean that all necessary care is covered. Among severely impaired school children with private health insurance coverage, only 22 percent had all of their physician visits paid by insurance. Data from 1980 show that approximately 421,000 non-institutionalized children incurred out-of-pocket expenses greater than 10 percent of family income and approximately 157,000 children had out-of-pocket expenses in excess of 30 percent of their family income.

Thus, although private insurance coverage is an important protection for most families with chronically ill children, coverage is neither complete nor comprehensive. Large numbers of chronically ill children are not covered and for those with coverage, benefits are often inadequate.

Medicaid helps fill some, but not all, of the gaps in private health insurance coverage for chronically ill children. Of course, in order to be eligible for Medicaid, the family of a chronically ill child must be poor. How poor one must be before becoming eligible varies tremendously among the states because the income level for program benefits is set by each state, often at a level well below the Federal poverty level. Families may also not qualify for Medicaid because of its stringent limit on assets. Benefit limitations may also leave families covered by Medicaid vulnerable to substantial expenses.

Thus, although Medicaid is an important financing source for poor children with chronic and disabling conditions, it falls short both in terms of the number of poor children covered and the level of comprehensiveness for many of those who are cover-

ed. Medicaid covers only about 60 percent of disabled children from families with incomes below the federal poverty level. Moreover, because Medicaid is a means-tested program for the poor, it offers no relief to moderate income families struggling to provide for their chronically ill child. Medicaid is not an alternative to private insurance for most families.

III. Policy Actions

Action to expand health insurance protection for poor children and for chronically ill children can be taken in smaller or larger steps. The overall basic strategy should be assuring adequate health insurance coverage of children of working families through employer health insurance plans, coverage of poor and near-poor children through Medicaid, with the option of Medicaid coverage on a contributory basis for any remaining uninsured children.

A. Short-term Options

Important steps could be taken toward improving coverage of poor children and chronically ill children with only modest budgetary impact. These include:

- Extending Medicaid coverage for a period of time after the mother becomes employed and leaves AFDC. Nine months would be a minimum period to provide some continuity of health insurance coverage.
- States should be given the option of covering children up to age 18 up to the federal poverty level.
- Employers who currently provide health insurance coverage to employees could be required to cover dependents of workers (unless covered under another employer plan), and include comprehensive prenatal, delivery, and infant care in the benefit package. These standards would follow the precedent established in the 1985 Comprehensive Omnibus Budget Reconciliation Act which required employer health plans to extend

coverage to employees and/or dependents for a period of time following termination of employment or divorce.

B. Longer-term Reform

When additional budgetary resources are available, more comprehensive steps could be taken. These include:

- Mandating Medicaid coverage for all pregnant women and children up to age 18 with incomes below 100% of the federal poverty level.
- Requiring all employers to provide minimal health insurance coverage to all full-time employees and their dependents. Benefits should include a ceiling on catastrophic expenses and comprehensive prenatal, delivery, and infant care.
- Medicaid buy-in should be an option for employers and individuals who wish to purchase Medicaid coverage. Premium contributions could be subsidized for low-income individuals and employers of low-wage workers wishing to purchase Medicaid coverage in lieu of private health insurance coverage for workers.

Testimony of the
Children's Defense Fund
Before the Senate Finance Committee
Regarding Medicaid,
The Maternal and Child Health Block Grant
And Other Matters Pending in the
Fiscal 1988
Budget Reconciliation Process

Presented by
Sara Rosenbaum
Director, Health Division

Mr. Chairman and Distinguished Members of this Committee:

The Children's Defense Fund (CDF) is pleased to have this opportunity to testify today regarding Medicaid, the Maternal and Child Health Block Grant and other pending issures in the Fiscal 1988 Budget Reconciliation process. CDF is a national public charity which engages in research and advocacy on behalf of the nation's low income and minority children. For fifteen years, CDF's health division has engaged in extensive efforts to improve poor children's access to medically necessary care, including both primary and preventive services, as well as medical care requiring the most sophisticated and costly interventions currently available. I have submitted a longer statement for the record and will present a summary of my testimony at this time.

I. The Health Status of Children

Both ends of the medical care spectrum -- preventive and intensive -- are vital to the health and well-being of children. All children need primary care, including comprehensive maternity care prior to birth, ongoing health exams and followup treatment, care for self-limiting illnesses and impairments (such as influenza or strep), and vision, hearing and dental care. Additionally about one in five children will be affected during childhood by at least one mild chronic impairment, such as asthma, a correctable vision or hearing problem, or a moderate emotional disturbance, which will require ongoing medical attention.

Beyond these basic health needs, a small percentage of children require more extensive and expensive medical care; and a

modest proportion of this latter group will face truly extraordinary health care costs over their lifetimes. About four percent of all children (a figure which by 1979 was more than double the percentage reported in 1967)[1] suffer from one or more chronic impairments resulting in a significant loss of functioning. Included in this group are children suffering from degenerative illnesses, multiple handicaps, and major orthopedic impairments. About two percent of all children suffer from one of eleven major childhood diseases, including cystic fibrosis, spina bifida, leukemia, juvenile diabetes, chronic kidney disease, muscular dystrophy, hemophilia, cleft palate, sickle cell anemia, asthma, and cancer.[2] Also included in this group are the several thousand children who are dependent on some form of life support system.

Finally, nearly 7 percent of all infants are born at low birthweight (weighing less than 5.5 pounds) each year.[3] Virtually all will require some additional medical services. About 18 percent of all low birthweight infants (approximately 43,000 infants) weigh less than 3.3 pounds at birth and will require major medical care during the first year of life. About 9600 infants will incur first year medical costs alone that exceed $50,000, and a portion will require ongoing care throughout their lives.[4] Low birthweight infants are at three times the risk of developing such permanent impairments as autism, cerebral palsy and retardation.[5]

II. The Health Needs of Children

Most children, even children with impairments, require relatively modest levels of health care. Only about five percent of all children incur annual medical costs in excess of $5,000, and only about 5 percent of these have annual costs exceeding $50,000.[6] However, both groups of children -- those with routine health care needs and those with high cost medical problems -- can be considered catastrophic cases, in either relative or absolute terms.

For low income uninsured families, even basic child health needs can result in catastrophic expenditures if the term "catastrophic" is measured in relation to a family's overall income. Between 1982 and 1985, the number of completely uninsured children climbed by 16 percent.[6a] In 1985, three quarters of the 11 million uninsured children,[7] and two-thirds of the more than 9 million uninsured pregnant women,[8] had family incomes below 200 percent of the federal poverty level. Poor and near-poor uninsured families, when confronted with even normal child health expenditures of several hundred dollars per year, face insurmountable health care barriers. As a result, uninsured low income children receive 40 percent less physician care and half as much hospital care as their insured counterparts.[9]

The uninsured are disproportionately likely to be children. In 1985, children under 18 comprised 25 percent of the under-65 population, but one-third of the uninsured under-65 population.[10] Moreover, they are disproportionately likely to be poor. Over 60 percent of all uninsured persons in 1985 had family incomes below 200 percent of the federal poverty level, and one-third had family incomes below 100 percent of the federal poverty level.[11]

Even a parent's access to employer insurance by no means assures relief for a child. In 1985, 20 percent of all uninsured children lived with a parent who had private coverage under an employer plan.[12]

The two main causes of children's lack of health insurance are the major gaps in the employer-based health insurance system and the failure of Medicaid, the nation's major public health insurance program for children, to compensate for the failings of private plans.

The Private Health Insurance System Is Leaving More American Children Uninsured

Our nation relies primarily on private health insurance to meet much of the health care costs of the working-age population and its dependents. Most of this private insurance is provided

as an employment-related benefit. Employer-sponsored health care plans are the single most important source of private health care coverage for Americans younger than sixty-five. In 1984, over 80 percent of all privately insured American children were covered by employer plans.[13]

Yet during the 1980's, dependent coverage under employer-provided health insurance plans has undergone serious erosion. In 1982, employer plans covered over 47 million non-workers, including 36 million children. By 1985, even though there were actually more workers covered by employer plans than in 1982 (88 million versus 84 million), the number of covered children dropped to less than 35 million.[14] The recent decline in employer-provided coverage has been most apparent among children for several reasons. First, in pursuing cost containment strategies, employers have frequently reduced or eliminated their premium contributions for family coverage.[15] As a result, lower income employees, faced with dramatic cost increases, have been forced to drop family coverage.

Second, the employer insurance system also completely excludes millions families at the lower end of the wage of scale -- the fastest growing part of the job sector. Thirty percent of all employers who pay the minimum wage to more than half their work force offer no health insurance.[16] As these young adult workers have families, the children are affected by their parents' lack of coverage.

Third, as the number of single parent households grows, the percentage of insured children declines. Because single parent households have only one wage earner, the probability that a child will have indirect access to an employer plan drops. In 1984, children in single parent households were about 3 times more likely than those in two parent households to be completely uninsured.[17] Thus, the employer-sponsored health insurance system excludes those children whose parents' employers either do

not offer any family coverage or else offer it only at an unaffordable cost. As a result of these trends, a child living in a poor working family is only about half as likely as a non-poor child to have private insurance.[18]

Medicaid, the Major Public Insurance Program for Families with Children, Is Covering Fewer Children

Medicaid, enacted in 1965, is the nation's largest public health financing program for families with children. Unlike Medicare, which provides almost universal coverage of the elderly without regard to income, Medicaid is not a program of universal or broad coverage. Because Medicaid is fundamentally an extension of America's patchwork of welfare programs, it makes coverage available primarily to families that receive welfare. With a few exceptions (including pregnant women and children younger than five with family incomes and resources below state-set Aid to Families with Dependent Children eligibility levels), individuals and families that do not receive either AFDC or Supplemental Security Income (SSI) are categorically excluded. For example, a family consisting of a full-time working father, mother, and two children normally is excluded from Medicaid, even if the father is working at a minimum wage job with no health insurance and the family's income is well below the federal poverty line. Moreover, even though states have had the option since 1965 to cover all children living below state poverty levels regardless of family structure states still fail to do so.[19]

In addition to its use of restrictive eligibility categories, Medicaid excludes millions of poor families because of its financial eligibility standards, which for most families are tied to those used under the AFDC program. In more than half the states, a woman with two children who earns the minimum wage (about two-thirds of the federal poverty level for a family of three in 1986) would find that she and her children are ineligible for coverage.[20] By 1986, the combined impact of

Medicaid's restrictive categorical and financial eligibility standards had reduced the proportion of the poor and near-poor covered by the program to only 46 percent--down from 65 percent a decade earlier.[20a]

As a result of improvements enacted by Congress in 1984 and 1986, many previously uninsured low-income pregnant women and children will be aided.

- The Deficit Reduction Act of 1984 (DFRA) mandated that states provide Medicaid coverage to all children younger than five with family incomes and resources below AFDC eligibility levels.

- The Deficit Reduction Act and the Consolidated Omnibus Budget Reconciliation Act of 1986 (COBRA) together mandate coverage of all pregnant women with income and resources below state AFDC eligibility levels.

- The Sixth Omnibus Budget Reconciliation Act (SOBRA) passed in late 1986 permits states at their option to extend automatic Medicaid coverage to pregnant women and children under age five with incomes less than the federal poverty level but in excess of state AFDC eligibility levels. Table I indicates that by July, 1987, 19 states had adopted SOBRA coverage.

  If fully implemented in every state, the SOBRA amendments will reduce by 36 to 40 percent the number of uninsured pregnant women and young children nationwide.[21]

However, even if fully implemented, these new laws will not compensate for Medicaid's growing failures. SOBRA's age limitations mean that Medicaid still will not reach children over age five with family incomes below the federal poverty level. Because of DFRA's age limits, in 19 states, poor children over age five are still excluded, no matter how severe their poverty, simply because they live with two parents and are beyond the age mandate of the 1984. Moreover, these new laws provide no relief for the millions of uninsured, nonpregnant, poor parents, whether working or unemployed.

Improvements enacted by Congress and the states in recent years are unlikely even to offset the decade of stagnation and erosion which Medicaid has experienced. In Fiscal Year 1985, Medicaid served 10.9 million children under age twenty-one--more than 400,000 fewer than were served in Fiscal 1978.[22] This drop

occurred despite the fact that Fiscal 1985 was the first year that the 1984 Deficit Reduction Act amendments were in effect, and it followed enactment by about a dozen states of additional Medicaid child coverage improvements. This decline occurred as the number of children in poverty rose by one-third and the number of uninsured children grew by 16 percent.

The Special Needs of Children with High Cost Health Problems

By expanding the number of children with health insurance, Congress would also provde extensive relief for children with high cost medical needs which arise as a result of serious illness or disability.

Medical problems disproportionately affect low income children who tend to be born at lower birthweight and suffer more frequent, and more severe illnesses and disabilities.[23] Thus, insuring more low income children would also assist many chronically ill and disabled children.

Among the 10% of children who have an illness or disability sufficiently serious to limit normal childhood activities, we estimate that there are about 400,000 poor and near-poor children with incomes below 200% of the federal poverty level who are completely uninsured. Moreover, even normative levels of insurance, public or private, are inadequate in the case of the most severely catastrophically ill or disabled infants and children. There are about 19,000 such children (9600 of whom are under one year of age) who annually incur more than fifty thousand dollars in health care costs.

The traditional notion of health insurance is that it provides protection against grave health costs. But over time the nation has developed public and private health insurance systems that are designed to meet normative, rather than high cost catastrophic, medical care needs. Both public and private health insurers have developed myriad ways to limit their exposure for high-cost illnesses and disabilities, in favor of providing subsidies for more routine health expenditures:

- Among employers responding to a major health insurance survey conducted in 1986, 73 percent indicated that their plans exclude coverage of preexisting conditions.[24] More plans now also contain riders that exclude coverage of certain conditions that may develop among enrollees, such as cancer.

- Only about 75 percent of plans offered by medium and large-sized firms between 1980 and 1985 contained protections against huge out-of-pocket costs borne by enrollees in the event of catastrophic illness.[25]

- Only 67 percent of mid-and-large-sized firms offered extended care benefits between 1980 and 1985, and only 56 percent offered home health benefits.[26]

- In 1977 only 8.3 percent of all children had unlimited private coverage for major medical benefits, and one-third had coverage for a quarter million dollars of care or less.[27]

- Fourteen state Medicaid programs place absolute limits on the number of inpatient hospital days they will cover each year, with some states limiting coverage to as few as 12-15 days per year.[28] About an equal number place similar limits on coverage of physicians' services. Others place strict limitations on such vital services as prescribed drugs and diagnostic services.

- Finally, Medicaid, like private health insurance frequently fails to cover extended home health and related services (including such non-traditional items as home adaptation). When such coverage is available, it may be provided on a case-by-case exception basis.

The question of whether private and public insurers should provide comprehensive but shallow, versus deep but limited, coverage is a complex one, particularly since so many American families need a financial subsidy to meet even basic health costs. While this issue is being resolved however, thousands of uninsured are inadequately insured children with chronic health problems face serious underservice, particularly if they are low income.

Recommendations

It is essential that all children -- infants or adolescents, healthy or sick -- have health insurance. Given the high cost of even routine health care, particularly in the case of poorer families, comprehensive health insurance is an absolute necessity. We support both legislation introduced by Senator Chafee, which would provide public coverage through Medicaid for families and children who are without coverage, as well as

legislation introduced by Senator Kennedy, which would expand the nation's private health insurance system to reach millions of working families.

We recognize, however, that Congress is still some distance away from enacting policies that would ensure adequate health coverage for all children. We therefore recommend enactment this term of both Medicaid and Title V Maternal and Child Health Block Grant reforms targetted on key groups of children with high priority needs.

Medicaid

- Enact S.422, the Infant Mortality Amendments of 1987. This bill, introduced by Senator Bradley and Congressman Waxman and cosponsored by many members, would add Medicaid coverage of children ages five to eight living below state poverty levels, as well as further strengthen states' capacity to serve poor and near-poor pregnant women, infants and young children. This bill has bipartisan support, and its passage was assumed as part of the Fiscal 1988 Budget Resolution.

- Phase in expanded Medicaid coverage for low income and disabled individuals as provided in S.1139 (Med-America): We strongly support legislation introduced by Senator Chafee earlier this year, which would permit states to extend Medicaid to low income families on the basis of an income-adjusted premium, and at cost to persons excluded from private insurance because of preexisting conditions. With over .35 million Americans uninsured, it is vital that until private insurance is more widely available there be established a public insuring mechanism established that will permit poor and disabled families to meet their basic health insurance needs.

- End states' discrimination against disabled children. Currently at least 5 states (Connecticut, New Hampshire, Indiana, Minnesota and Missouri) categorically exclude from their Medicaid programs children who receive SSI benefits, unless they are also eligible under some other Medicaid coverage category. This exclusionary practice grows out of an obscure legislative provision dating back to the 1972 enactment of SSI. It is time that all states extended coverage to all disabled children who meet these states' financial eligibility standards. Some of the nation's most severely disabled children would be assisted.

- Mandate coverage of so-called "Katie Beckett" children. In 1982 Congress gave states the option of providing Medicaid to any child under 18 would be eligible for SSI if institutionalized, who could be cared for in a home or community setting, and whose home care would be no more costly than his or her institutional care. By definition, this was a no-cost eligibility option; yet only a dozen states have taken it. As a result, hundreds of children who might return home if they had Medicaid continue to languish in institutions because

their eligibility would cease immediately upon deinstitutionalization. All states should be required to furnish home and community coverage to children, who satisfy the 1982 standards.

- Provide Medicaid to children with family incomes under 200 percent of the federal poverty level who have illnesses, disabilities and conditions that limit or impair normal childhood activities. In 1974 and 1986 Congress enacted landmark legislation guaranteeing special education and early intervention services to infants and children with disabilities that impair normal activity and inbibit proper growth and development. Many of these children suffer simply from a learning disability or require assistance only in meeting routine health care costs. Others, however, have serious medical impairments that limit their ability to grow and develop and perform normal childhood activities. Special education funds do not provide coverage for these children's medical needs. Studies of uninsured children in special education programs conducted by the Robert Wood Johnson Foundation and the Havard School of Public Health determined that children in special education who were low income and uninsured received significantly less medical care.

  If the goals of the special education and early intervention laws are to be reached, low income children with activity limitations must also be provided with Medicaid as complement to their educational benefits. We strongly recommend passage of such coverage, phased in over the next several years, beginning with 0-3 years olds who are now eligible for early intervention services under Public Law 99-457. Coverage should be furnished free of charge to children with family incomes below the federal poverty level and in accordance with an income-adjusted premium for children with incomes between 100 and 200 percent of the federal poverty level.

- Enact Medicaid improvements for working poor families leaving AFDC. Amendments recently added to the House Welfare Reform bill by the Energy and Commerce Health Subcommittee, contain significant Medicaid improvements for the working poor. These improvements can stand on their own in the Reconciliation bill. The committee bill would extend to 24 months the four-month Medicaid transitional period now provided to most working recipients losing AFDC. It would also give states the option of furnishing benefits for an additional 18 months. During most of the 24 - month period benefits could be furnished in accordance with an income-adjusted premium. This bill constitutes not only a strengthening of the current Medicaid work incentive but also an important modification of the existing Medicaid system that will permit the program to reach many working poor persons not covered by private insurance.

The Title V Maternal and Child Health Block Grant

- Establish a special Title V program to assist families with children with high cost illnesses and newborns and infants who incur catastrophic costs. Of the 9600 infants with medical costs in excess of $50,000 annually, nearly 20% will be completely uninsured, and

many of the rest will have inadequate or no protection for the range of institutional and noninstitutional care they need. We urge establishment of a fund for these children, accompanied by a strong system of case management for all children with annual health costs exceeding $5000. Full year costs of this proposal in Fiscal 1988 would be approximately $500 million.

The Title XX Social Services Block Grant

- Include in Reconciliation a $200 million increase in the Title XX Social Services Block Grant, the major federal source of funds for a wide range of essential social services. Many of these services are preventive and designed to reduce the incidence of more costly alternatives. Title XX is the primary source of federal support for child care for low-income parents who are seeking to become self-sufficient by working or participating in training programs. It is also a critical source of funds for protective services and for children suffering from abuse and neglect. Between 10 and 20 perent of Title XX funds aid older adults, enabling them to benefit from homemaker and home services, day care, counseling, protective and health services, home delivered meals, employment, housing improvement and recreational services. Finally, Title XX is a key source of non-institutional, community-based services for the disabled.

  Despite the fact that Title XX provides this core funding for so many essential programs, it is now funded at $600 million less than it would have been if it had not been cut in 1981. In fact, when inflation is considered, funding for Title XX is half of what it was a decade ago, when Title XX was authorized at $2.5 billion.

  Without a restoration of funds, states will not be able to meet the needs of their most vulnerable young, elderly, and disabled citizens. Today, 23 states provide fewer children with day care services than in FY 1981. When inflation is factored in, 29 states are spending less now than in FY 1981 for child day care services and, nationwide, such expenditures are down by 12 percent. Some states also have totally eliminated adult day services for person with handicaps. Remaining states have huge waiting lists.

In all states, child welfare agencies are being hard-pressed by dramatic increases in reports of child abuse and neglect. In 1985, there were approximately 1.9 million such reports, a 10 percent increase from 1984, and a 58 percent increase since 1981. As the value of Title XX funding erodes, states are being forced to make potentially tragic choices among competing demands for staff and resources. As a result of the need for increased protective service investigations, efforts to reunify children already in care with their families or to place foster children in adoptive homes have been slowed in some states. Others have limited services aimed at averting more serious family crises.

National Commission on Children

Mr. Chairman, because our goal is to educate the nation about the needs of children and encourage preventive investment in children, the Children's Defense Fund also supports Senator

Bentsen's proposal to establish a National Commission on Children. The activities of such a commission could help better inform the nation on the status of America's children and consider ways to better ensure their optimal mental, emotional, and physical development. We believe that the well-being of children should be a part of our national policy debates, and we hope that a commission will succeed in highlighting the unmet needs of our children.

Thank you very much. We look forward to working with the Committee on the development of these vital initiatives.

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Testimony of the

National Perinatal Association

Presented by

Robert Cicco, MD

Mr. Chairman and Distinguished Members of the Senate Finance Committee, I am Dr. Robert Cicco, MD, the Legislative Chair of the National Perinatal Association and a neonatologist at Western Pennsylvania Hospital in Pittsburgh, as well as the father of four sons. I am pleased to have the opportunity to address the Committee on the health care needs of mothers and children and long-term and short-term strategies to improve their health.

The National Perinatal Association (NPA) is an organization comprised of 10,000 members including physicians, nurses, nurse-midwives, dieticians, social workers, consumers, and other perinatal professionals. The term "perinatal" refers to the period shortly before and after birth, from the twentieth to the twenty-ninth week of gestation to one to four weeks after birth. We are, in essence, concerned with the health of mothers and infants. Our organization is unique in that it represents multidisciplinary professionals brought together under a common bond, the desire to improve the health of America's mothers and infants. Among our top priorities are: one, improving infant mortality; two, improving access to care; three, expanding Medicaid; and four, finding solutions to financing catastrophic care.

In the mid-seventies, just around the time the NPA was formed, I was completing my first clinical rotation as a third year medical student in a neonatal intensive care unit (NICU). In my first encounter with the NICU, I became interested in pediatrics. As a neonatologist I work with premature and low birthweight infants (under 5 1/2 pounds). Often these babies are seriously ill. The medical consequences of low birthweight are serious; low birthweight infants are twenty times

more likely than normal weight infants to die in their first year of life. And low birthweight accounts for two-thirds of all infant deaths within the first twenty-eight days of life (1). Today, October 2, I have the pleasure of celebrating my son's thirteenth birthday. Yet, in my work, I often have to tell parents that they will not even have the opportunity to celebrate their child's first birthday.

Low birthweight infants that survive often suffer from disability throughout their lives and require extensive medical attention. They are more likely to suffer from long-term handicapping conditions such as mental retardation, cerebral palsy, autism, epilepsy, chronic lung disease, and growth and development problems. The medical costs for care of these low birthweight infants are enormous. The average cost for care of an infant in a neonatal intensive care unit can range from a few thousand to hundreds of thousands of dollars depending on the severity of the illness and the length of stay. The emotional and social costs are more difficult to calculate, but they are enormous as well.

Giving birth to a seriously ill infant also has a substanial effect on a family. The medical costs alone, even when the family is insured, create financial stress. This only adds to the emotional trauma involved. I would like to tell you about two families that faced this hardship.

A boy was born to a married couple from southern Indiana. His father was a bank president and his mother was the Assistant Director of Nursing at a small county hospital. The baby's parents had group medical insurance through their employers. The infant was born with short gut syndrome, a condition in which the intestines are not long enough to allow adequate digestion for growth. This was compounded by severe neurological deficits, and the child was hospitalized at birth for ten months. Due to the infant's complex needs, the parents wanted to place their

baby in a skilled nursing facility. They located one that agreed to accept him. However, funding became a major issue. The parents' insurance allowed for no nursing home coverage and only minimal home health care benefits. Because the parents were married with good incomes, they were ineligible for any Medicaid assistance. They could not afford the cost of nursing home care, so they were left with the following options:

1) They could divorce and the mother could quit her job to make her eligible for AFDC and Medicaid, thus enabling a nursing home placement; or
2) the mother could quit her job and stay home with her son.

The mother chose the latter. In order for the child to grow, an intravenous tube was placed to infuse calories directly into the vein. Fortunately, the mother's nursing backgound enabled her to be his primary care provider, but she was tied to the house twenty-four hours a day. This family is more fortunate than most as it could afford to have only one parent work and the mother, being a nurse, was qualified to take care of the infant at home.

The second case study demonstrates an even broader spectrum of problems by families of high risk infants. An infant with multiple, severe congential anomalies was born to a couple in their early thirities. The mother was a school teacher, on leave without assistance, and the father was a furniture store manager. The baby was hospitalized for two months with very complicated care. He had a tube placed directly into his trachea to allow breathing and one into his stomach for feeding. He also had severe tightening of the muscles and required oxygen. The parents had excellent insurance coverage for hospital care, but they did not have nursing home benefits or extensive home care benefits. The family needed a nursing home placement, as they did not feel they could provide for him in their own home. He had essentially no rehabilitation potential -- he was blind,

severely brain damaged and probably deaf. A skilled nursing home about 60 miles from their home (the closest one) agreed to accept him, but financial barriers made this option infeasible. The family was ineligible for Medicaid or other assistance because their income was above the financial limitations. They explored numerous funding resources, to no avail. The parents even attempted to go through the county welfare system and would have given up custody of their son to facilitate placement, but that was not allowed. As the parents could not afford the cost of nursing home care, arrangements were made for a private foster home placement for which the parents paid $300 - $350 a month. The baby died while in the foster care placement.

These two case studies demonstrate the common inadequacies of private health insurance coverage for chronic or catastrophic illness. If these are the problems that middle-class families face in terms of catastrophic illness, you can imagine the greater hardship faced by low-income, working families and the poor who are more likely to be uninsured.

One of the most difficult aspects of my job is witnessing death and disability among infants and knowing that many of their conditions were preventable. The contrast between the expensive, high technology care used for premature and low birthweight babies and the inexpensive, routine prenatal care for pregnant women clearly illustrates the need to improve access to prenatal care. In 1984, more than 20 percent of all births in the United States were to women who failed to receive prenatal care during the first trimester (2). On September 30th, 1987, GAO released a prenatal care study in which 1,157 women were interviewed who either had no insurance or were enrolled under the Medicaid program. The study found that 63% of the women received inadequate prenatal care (3). We no longer have to document that early, comprehensive prenatal care improves pregnancy outcomes. Numerous research studies have already done that. We know that providing prenatal care is cost effective.

The Institute of Medicine estimates that every dollar spent on prenatal care saves $3.38 in medical care to low birthweight infants in their first year of life (4). We know this. What we, as a nation, are still figuring out is how to create and fund programs that ensure proper access to health care. As a nation facing a growing deficit, we can not afford to deny access to prenatal care to women This action only increases medical costs due to the births resulting in death and disability.

NPA believes in investing in our future generations. The current high infant mortality rate in the United States demonstrates that we still have not provided adequately for our nation's children. Since 1950, the United States has not improved its infant mortality rate as rapidly as other industrialized nations. In 1950, the infant mortality rate of one of our greatest economic competitors -- Japan -- ranked seventeenth and ours ranked sixth among twenty industrialized nations. Yet in 1985, Japan's infant mortality rate ranked <u>first</u> while ours ranked <u>last among the same twenty industrialized nations</u> (5). Clearly, we have lost ground in more than just electronics and automobiles. NPA believes that it is time to re-invest in our nation's future by ensuring quality prenatal care to all pregnant women.

In the long-run, we believe this can only by accomplished with the support and commitment of both private and public sectors. We, along with other national organizations like the Institute of Medicine, the Robert Wood Johnson Foundation, the Southern Governors' Association and the American Public Health Association, see the need for the federal government to take leadership in assuring access to care. As early as 1984, the National Perinatal Association passed a resolution urging the development of federal legisation that would improve the access to care. Currently, we support legislation introduced by Senator

Chafee that would provide catastrophic health care coverage for children in their first year of life. We recognize, however, that more immediate, short-term remedies are needed.

NPA recommends, as a short-term solution, that Congress enact S.422 and H.R. 3288 (orginally H.R. 1018), the Medicaid Infant Mortality Amendments of 1987 introduced by Senator Bradley (R-NJ) and Congressman Waxman (D-CA). This bill would extend Medicaid eligibility to children ages five to eight living below state poverty levels as well as allow states the option to extend Medicaid coverage to pregnant women, and infants up to age one, with family incomes up to 185 percent of the federal poverty level. It would also provide states the option of covering all children under age eight with family incomes below the federal poverty level.

NPA also recommends that the federal government create programs that would be implemented in all states. Currently, the 1986 SOBRA legislation which allows states the option to extend Medicaid elgibility for pregnant women with incomes up to 100 percent of the federal poverty level has not been implemented in eighteen states. A substantial number of women would have access to prenatal care if ALL states adopted this option.

NPA commends the recent federal efforts to improve health care for the poor through the Deficit Reduction Act of 1984, the Consolidated Omnibus Budget Reconciliation Act of 1986, and the Sixth Omnibus Budget Reconciliation Act which all expanded the eligibility to Medicaid. In addition, the establishment of the National Commission to Prevent Infant Mortality demonstrates an awareness and commitment to improve our infant mortality rate. NPA urges that Federal action on the problems of access to health care and infant mortality not stop there but continue until adequate care is accessible to all.

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CHILD HEALTH PROGRAMS

Presented by

JEROME PAULSON, M.D., F.A.A.P.

Mr. Chairman, I am Jerome Paulson, M.D., a pediatrician and member of the American Academy of Pediatrics Council on Government Affairs. I am here today on behalf of the Academy, Ambulatory Pediatric Association, American Association of University Affiliated Programs for the Developmentally Disabled, American Association on Mental Retardation, American Occupational Therapy Association, American Pediatric Society, Association for Retarded Citizens, Association for Children and Adults with Learning Disabilities, Association of Medical School Pediatric Department Chairmen, Autism Society of America, Child Welfare League of America, Inc., Epilepsy Foundation of America, Society for Adolescent Medicine, Society for Pediatric Research, and United Cerebral Palsy Association. I am delighted to have this opportunity to share with you our considered views on Medicaid, catastrophic health insurance for children, the maternal and child health block grant and other issues relevant to budget reconciliation.

To date, Mr. Chairman, despite your best efforts and those of your colleagues on this panel, there remains more promise than progress in these vital programs and plans. But increasingly there are signs that the times are changing. Here in Washington and across the country Americans seem to be genuinely awakening to the improvident neglect of our children in recent years. So it is with renewed optimism today that we look forward to working closely with you to remove financial barriers to ambulatory, hospital and home care for children -- an effort that would dramatically improve our children's health and could help ensure them long and productive lives as American citizens.

Certainly, recent developments have proved distressing and demand attention. The decreasing access to care that poor children are currently experiencing appears to correlate with an alarming rise in preventable morbidity and mortality. This can be documented by the increased incidence of preventable childhood diseases, such as measles and pertussis, and the weakening decline in infant mortality rates since 1982. To be sure, 20 states report that in certain regions there has been an actual increase in the infant mortality rate. In addition there is the growing rate of teenage pregnancies -- one million annually among 15-19 year olds.

Medicaid, for its part, is still the largest and most comprehensive public health care program for children. However, in the past decade of rapidly rising health care costs, this joint federal-state health plan for the poor protects fewer and fewer low-income Americans. Enrollment has declined in recent years from a high of 23 million recipients in 1977 to 21.2 million in 1984. By 1985

Medicaid reached only 46 percent of the poor and near-poor, down from 65 percent a decade before. This drop followed 12 years of rising enrollment since the program's creation in 1965.

Also of adverse consequence are wide variations in state eligibility and benefit rules, which cause marked inequities for Medicaid recipients. The General Accounting Office reports that spending in fiscal 1985 varied from a low of $821 per enrollee in West Virginia to a high in New York of $3384. Many states do not cover people with incomes well below the federal poverty line -- in nine states, three-quarters of the poor are ineligible. Another egregious variation, to go no further, is that six states (Hawaii, Montana, New York, Pennsylvania, Rhode Island and Wisconsin) cover all five major optional groups of recipients even as Indiana and Missouri cover none.

Some sunlight was visible in 1986, as a number of states complied with congressionally inspired opportunities to enhance Medicaid. The Consolidated Budget and Reconciliation Act of 1985, enacted in April of last year, required states to extend pregnancy-related services to all pregnant women with family incomes below AFDC-eligibility levels. Arizona now pays for medical care needed by children under the age of six in any household receiving food stamps, or with a family income below the federal poverty level. The Sixth Omnibus Budget Reconciliation Act of 1986, signed into law last fall, provides states the option of extending Medicaid to pregnant women and children under age five (on a year-by-year, phased-in basis) whose family incomes exceed AFDC-eligibility levels but are less than the federal poverty level. Movement of states toward embracing this important expansion of eligibility has been encouraging. Twenty-two states have passed this option, and it is expected that at least 7 more will follow suit. Fortunately, in all but two of these 22 states, the income level adopted was the maximum -- 100 percent of the poverty line. The sad news is that 15 states have rejected the option while another 6 are considering it.

In fact, every year since 1983, Congress, despite the specter of punishing deficits, has successfully fashioned marginal, incremental progress in the Medicaid program specifically aimed at the promotion of maternal and child health. Data from a variety of sources confirm that Medicaid expenditures for children are inexpensive relative to other populations. (Yet children continue to constitute roughly 50.3 percent of Medicaid recipients, while receiving only 19.3 percent of program expenditures.)

Meanwhile, other extremely serious health care access problems persist:

° One-third of all uninsured pregnant women and more than 30 percent of uninsured children have family incomes between 100 and 200 percent of the federal poverty level. These meager incomes are too high to qualify for Medicaid but inadequate to buy either necessary health care or private health insurance.

° Eighteen states still fail to extend Medicaid coverage to children over age five with incomes below AFDC-eligibility levels if they live in two-parent, working families.

It is thus imperative that maternal and child health advocates continue to press for a Medicaid program that is both equable and equitable. Indeed, there are several significant measures before you which should be enacted as part of the reconciliation bill.

First, Senator Bill Bradley's (D-N.J.) legislation (S.422) would 1) permit states to cover pregnant women and infants with family incomes under 185 percent of federal poverty; 2) permit states to accelerate coverage of certain children addressed in the new 1986 law, i.e., children under age five with family incomes below 100 percent of federal poverty; and 3) extend Medicaid coverage by FY 1991 to all children under age eight with family incomes and resources below AFDC financial eligibility levels.

This proposal would potentially aid 79,000 pregnant women and 239,000 children under age five in 1988 at a cost of only $65 million. It is especially important because private and public insurance mechanisms remain inadequate, because we know many pregnant women and children fail to receive needed health care as a result of gaps in insurance coverage, and because investing in preventive and primary health care is effective and economical. The Academy strongly supports inclusion of the Bradley amendments in the budget reconciliation bill, and applauds the senator for his continued leadership.

Second, we urge you to adopt provisions included in the House Energy and Commerce reconciliation package that would allow states to extend Medicaid coverage for six months, with no premium requirements, to families who lose cash-assistance benefits because of earnings. At the conclusion of the mandatory six-month period, states would be required to offer health coverage for an additional 18 months to families who continue to work. During this mandatory period, states could, at their option, extend health care coverage with an

income-related premium for an additional 18 months; state costs for this optional coverage would qualify for federal Medicaid matching funds. Thus, the total mandatory coverage period would be 24 months; the total potential coverage period, if a state elects, would be 42 months. These provisions would apply to individuals who leave cash assistance due to earnings on or after January 1, 1988.

Third, we urge you to include language in budget reconciliation to ensure that the provision in the 1984 Medicaid amendments extending coverage to newborns of Medicaid eligible mothers is properly implemented. As you are aware, Section 2362 of P.L.98-369 requires that states automatically extend care to babies born to Medicaid recipients for up to one year so long as the mother remains eligible for Medicaid assistance and the baby continues to live with the mother. This provision has been added because infants all to often are denied urgent medical care because of delays in the eligibility certification process.

Because HCFA has not given any direction, states' implementation of this provision has been disparate. Some have mothers use their cards in their babies' behalf; other states require hospitals to issue cards to the newborn; others have done nothing.

A logical recommendation -- developed by the Children's Defense Fund -- would be to require states to instruct providers to submit claim under the mother's ID during the automatic eligibility period. The baby would not only be entitled to the coverage but would have solid evidence of the entitlement. Given that such language would merely ensure implementation of the 1984 amendments, we do not believe there would be significant additional costs.

We would also bring to your attention -- and recommend inclusion of -- demonstration programs to reduce infant mortality by improving the access of eligible pregnant women and children under Medicaid to obstetricians and pediatricians. The demonstration projects would fund innovative approaches to increasing the participation of pediatricians and obstetricians by means such as guaranteeing continuity of coverage and expediting eligibility determiners; decreasing unnecessary administrative burdens; assisting in securing or paying for Medicaid malpractice and improving compensation through increased payment rates, expediting reimbursement and establishing global fees for pediatric and maternity services. The Secretary would be required to report to Congress not later than March 1, 1990 on the results of the demonstration projects.

Indeed, as the newly released GAO report concluded, almost two-thirds of pregnant women who are on Medicaid or who lack health insurance receive inadequate medical care during their pregnancies, a major contributing factor to high infant mortality rates. A survey of women in 32 U.S. communities found that women who had either Medicaid or no health insurance were far less likely than women with private insurance to seek care during the first three months of pregnancy, as is recommended, or to see a doctor at least nine times during pregnancy. It found that 63 percent of the 1,157 women surveyed had inadequate prenatal care. More than 12 percent of the women had low birth weight babies, compared with a national rate of less than 7 percent. It is our belief that increased participation by pediatricians and obstetricians-gynecologists will result in improved access to care and improved health status of pregnant women and children. This may also reduce overall costs if pregnant women and children substitute private physicians' offices for expensive emergency rooms and hospital clinics.

A second major concern to child advocates -- particularly those involved with children with special health care needs -- is the issue of catastrophic health insurance for children. As you are well aware, the catastrophic expenses incurred by children are a significant problem. During the past six months, several themes relative to the needs of children and families who incur catastrophic costs have emerged. First, although more information is necessary, the available empirical data indicate that the number of children who incur catastrophic expenses, compared with the eldery population, is smaller in absolute terms and proportionally. Second, by nature, children's catastrophic expenses are long-term or even lifelong, thus pointing to the need for improved home- and community-based care options. Third, given the varied requirements of these children and their families, there is a pressing need for care coordination to help ensure that these children and their families receive all the necessary services in a coordinated, financially sound fashion.

A true "solution" to the myriad of issues surrounding children's catastrophic health expenses will require a thorough and comprehensive examination. As such, we strongly urge the committee to convene a series of hearings on the issue of children's catastrophic expenses -- to better define the population, their costs and unmet needs, and to examine the array of proposals being put forth.

There are several significant proposals that merit your immediate attention -- proposals consistent with previous Medicaid expansions that would set the stage for consideration of a more comprehensive catastrophic policy for children. Senator John Chafee's (R-R.I.) Med America Act of 1987 (S.1139) provides a number of significant reforms for the millions of uninsured and underinsured. Of particular import, this bill would completely sever the eligibility tie between Medicaid, AFDC and SSI; allow individuals at or near the federal poverty level to "buy in" to Medicaid; and allow those in excess of 200 percent of the federal poverty level who have been denied health insurance because of pre-existing conditions, or who have exhausted their insurance benefits, to purchase Medicaid. Further, states that elect this option would be required to provide a standard benefit package that does not inordinately expand existing state commitments. The Academy and other organizations represented today support this bill, which clearly reflects the farsightedness of its sponsor. We also appreciate that Med America is an ambitious proposal. As such, we urge you to consider during the process of budget reconciliation the provisions in the legislation that would allow individuals who are denied insurance because of a pre-existing condition, or who have depleted all their insurance coverage, to purchase Medicaid, at a state option.

Indeed, given the limitations of the current economy, a more limited and perhaps more feasible measure, which is based on the principles embodied in Med America is Senator Durenberger's Medicaid amendments for chronically ill children and children with disabilities. Although consistent with the principles embodied in Med-America, this bill is unique in that it would extend Medicaid coverage to individual children with special health care needs and not the whole family. Under Senator Durenberger's bill states would be allowed to extend Medicaid coverage to chronically ill and children with disabilities in families whose income is under 185 percent of poverty. Care and services under the program would be furnished in accordance with an individualized written health care management plan developed under the direction of the designated case management agency. The plan would emphasize delivery of services in the least restrictive, most effective setting within the community. The health plan would ensure that comprehensive health care is provided and that, where appropriate, such care is combined with other relevant educational and social services provided by public and private agencies.

Today, an estimated 5 percent of all children under the age of 18, or 3 million children, suffer from a chronic illness or disability that significantly limits normal childhood activities; for example, juvenile diabetes, severe asthma, spina bifada, cystic fibrosis and mental retardation, all chronic diseases. Conditions classified as chronic share certain characteristics: they are costly to treat; require regular medical attention and health related services; may run an unpredictable course, and interfere in daily life and normal growth and development. Unlike an acute illness from which a child can recover, chronically ill children may never get well. The child and his or her family must deal with the disability on a permanent basis. Good, regular health care, however, can enable a chronically ill child or a child with a disability to function at his or her optimum and avert more costly hospitalizations.

For a low-income family, the regular and specialty health care services that may be required for a child with a chronic illness or disability can impose a tremendous financial burden. Without adequate care, the condition is likely to become more severe and result in complications. Unfortunately, approximately one-third of poor children and one-fourth of near poor children with chronic illnesses and disabilities are uninsured. Many others are underinsured. According to a recent study of access to health care for children with disabilities, the likelihood of seeing a physician was 3.5 times higher if the child had insurance coverage. Thus, without adequate health insurance, these children are not likely to receive the health care they desperately need to overcome the barriers to a happy, thriving childhood.

As such, we strongly recommend enactment of the Medicaid Chronically Ill and Disabled Children Amendments as part of budget reconciliation. This legislation is consistent with previous movement on the Medicaid program, would facilitate the coordination and development of a comprehensive delivery system at the state level, and would help serve children who are most in need. If enacted this legislation would set the stage for the committee to address the truly "catastrophic" needs of children.

While Medicaid funding has progressed however marginally over the past four years, the maternal and child health block grant is at a standstill. Aside from a minimal infusions, funding has remained virtually flat.

The purpose of the MCH block grant is to enable each state to assure mothers and children access to quality health services, reduce infant mortality and incidences of

preventable diseases and handicapping conditions among children, provide rehabilitation services for children who are blind and children with disabilities under the age of 16 and provide various services for children with special health care needs. Clearly, these are worthy goals. How well the program has been able to meet these goals, given limited funds, is unclear.

Specific recommendations with respect to the MCH block grant are not well formulated -- and cannot be -- absent oversight hearings to review the implementation of this important program. Since this program was enacted in 1981, Congress has yet to exercise its oversight authority to review the implementation of this program or look to needed modifications and fiscal stability. The Title V program, which underpins the MCH block grant, has celebrated its 50th anniversary. It is now time to look at the directions we must take over the next 50 years.

Indeed, the medical, social, and health care environments have changed dramatically since the enactment of this block grant, both in areas of medical technology and treatment and financing for an array of needed services. It is important that we examine the design and ability of this system to meet the complex needs of today's children and their families -- needs that involve a range of services from health, education, social services and other arenas. As with Medicaid, the MCH block must be assessed with respect to its responsibility to children and families for preventive, sick and catastrophic care coordination. The MCH agency at the state level is a logical recipient of monies to benefit children -- in fact, it may be the only place where such funds could be protected. However, we must first define exactly what needs to be done. What are these children's and their families' unmet needs? What kinds of interagency agreements are necessary to develop a truly coordinated system of care? What and where are the existing programs that could serve as role models for the nation? And, if more dollars are given to the system, should they go to service delivery, care coordination, or both? Indeed, oversight of the MCH block grant should not be a myopic assessment -- it should focus broadly on how maternal and child health programs should interlock more effectively to establish a coordinated system of child health care.

As we strive to fashion a more comprehensive system to address the needs of children, let us not take a band-aid approach to large holes in the so-called safety net. Rather, let us reason together in a focused oversight hearing to build a firm foundation with the capacity to provide the necessary comprehensive, high-quality care for all our children. Dollars may indeed be the answer,

but they must be fully utilized to reach as many children as possible in a system that is designed to do just that.

Another issue moving to the top of the agenda is funding for the childhood vaccine compensation legislation, P.L. 99-660, which passed last session. This issue is particularly pertinent to mention today because of its fiscal impact on the MCH Block and Medicaid. Without a compensation system, vaccine prices will continue to rise and many of our children will be at risk for totally preventable diseases. The cost of fully immunizing a child in the public system has gone from $6.49 in 1982 to $54.84 today. In our quest to address the health needs of children, we cannot lose sight of the most basic of our preventive health programs. We would urge you to take advantage of this opportunity to resolve the funding issues that currently block the implementation of this program. Specific recommendations will be provided pending House action within the next two weeks.

Finally, Mr. Chairman, we support passage of S. 1711, Senator Bentsen's proposal, for a National Commission on Children. As is obvious from the previous testimony, the need for such a body is clear and overdue. Indeed, the United States is the only major western country without a top level government agency devoted exclusively maternal and child health issues. We look forward to working with you and the commission to develop a true, sound, comprehensive child health agenda for America's children.

THE AMERICAN COLLEGE OF OBSTETRICIANS AND GYNECOLOGISTS

on

CHILD HEALTH PROGRAMS AND PROPOSALS

Presented by

Charles E. Gibbs, MD, FACOG

Mr. Chairman, Members of the Committee, I am Charles E. Gibbs, MD an obstetrician-gynecologist from San Antonio, Texas, and a member of the ACOG Committee on Health Care for Underserved Women. I'm delighted to be here today testifying on behalf of the College. No debate is more important than how to get children off to a healthy start. In these days when we are forced to make difficult choices because of budget considerations, this choice is an easy one. It's a question of whether we pay now or pay more later.

The relationship between prenatal care and the prevention of infant mortality was well documented in the 1985 report of the Institute of Medicine (IOM) Preventing Low Birthweight. The IOM found that "the overwhelming weight of the evidence is that prenatal care reduces low birthweight," a condition associated with two-thirds of the deaths in the neonatal period and 20 percent of postnatal deaths. Moreover, the IOM reported that "a major theme of virtually all the studies reviewed is that prenatal care is most effective in reducing the chance of low birthweight among high-risk women, whether the risk derives from medical factors, sociodemographic factors, or both."

Do all pregnant women uniformly receive good prenatal care? The answer is no, and the evidence for this is seen in the neonatal intensive care units of hospitals throughout the country. Not only has there been no progress since 1979 in getting more women into early prenatal care, the number of women who obtain late or no prenatal care has increased since 1982. In 1985, the latest year for which figures are available from the National Center for Health Statistics, 24 percent of mothers failed to begin prenatal care in the critical first trimester of pregnancy. Five percent of white women and 10 percent of black women received late or no prenatal care. The data shows that states with increases in the proportions of mothers receiving late or no care substantially outnumber states with declines.

Evidence of an unmet need for maternity coverage comes from studies which show that 17 percent of women of childbearing age are uninsured. Researchers at Vanderbilt University discovered that delivery of a child is the most frequent cause for hospitalization

of patients who lacked insurance. In the United States today we fail to assure the birth of healthy children, because we aren't doing what we already know will work.

MEDICAID ELIGIBILITY

Medicaid is the single most important source of care for low income pregnant women and their children. An estimated 15 percent of all births in 1984-85 were paid for by Medicaid. The problem with Medicaid is that far too few of the poor qualify. Eligibility for Medicaid services varies greatly among the states. In 1985 most states set their eligibility levels for Medicaid benefits at or below 50 percent of the federal poverty standard. In my own State of Texas, only 10 percent of births are subsidized by Medicaid and, due to very stringent eligibility criteria, 70 percent of women below the federal poverty standard don't qualify.

During the past several years, Congress has taken significant steps to address the infant mortality problem by expanding Medicaid eligibility for maternity care to more low income pregnant women. The Omnibus Budget Reconciliation Act of 1986 (OBRA) allows states to provide Medicaid benefits to all pregnant women with annual family incomes below the federal poverty standard of $8,738 for a family of three. The OBRA provisions give states the option of raising eligibility and receiving vital federal matching payments of 50%-80% of program expenditures.

In the state legislative sessions completed since the enactment of OBRA, preliminary reports show that 25 states have enacted some expansion of Medicaid eligibility or services for pregnant women. Hopefully more will follow in future legislative sessions. Although it is too early to assess the impact of these changes, we believe they will result in more women obtaining prenatal care.

Even for families with incomes above poverty, the cost of having a baby for those who lack insurance can be prohibitive. The Health Insurance Association of America (HIAA) estimates that in 1986 the total medical cost of having a baby was $2,560 for a normal delivery and $4,270 for a cesarean delivery. ACOG supports S. 422, the Medicaid Infant Mortality Amendments of 1987, which will build upon the progress made in preceding years by allowing states to extend Medicaid benefits for pregnancy related care to pregnant women with family incomes up to 185 percent of the federal poverty threshold, that is, to $16,165 for a family of three. These amendments, which are included in the FY 1988 reconciliation bill reported by the House Energy and Commerce Committee, will go a long way towards assuring that no pregnant woman lacks prenatal care because she cannot

afford to pay for it. The logic behind this step is irrefutable: prenatal care is not only effective in reducing low birthweight and infant mortality, it is cost effective. The IOM report concluded that for every dollar spent for prenatal care among a targeted high risk population, $3.38 could be saved in the total cost of caring for low birthweight infants requiring expensive medical care.

Some states have already shown interest in extending services to uninsured pregnant women with incomes above the federal poverty standard. Florida, Massachusetts, Michigan, Minnesota, New York, Rhode Island, and Washington have established programs to provide at least some pregnancy-related services for women with incomes above the federal poverty standard. Enactment of the Medicaid Infant Mortality Amendments of 1987 would reward these states for their initiative and provide the incentive for other states to follow suit.

AVAILABILITY OF CARE

In addition to addressing the issue of the pregnant patient's eligibility for reimbursed care, the ACOG urges you to begin to address the issue of the availability of pregnancy related care to Medicaid recipients. Pregnant women who are eligible for Medicaid services have difficulty obtaining prenatal care, in part because clinics are overburdened and many physicians in private practice are unwilling to accept Medicaid patients. Recent changes in the law expanding eligibility have not addressed all the access problems faced by pregnant women.

Studies of participation in Medicaid by obstetricians rely on self-reported data and show participation rates ranging from 46 percent of obstetricians in private practice (the Alan Guttmacher Institute, 1985) to 64.4 percent of all obstetricians (HCFA-NORC, 1978). Preliminary data from an ACOG survey conducted this year show that 64 percent of obstetrician-gynecologists sampled who provide obstetric care do so for Medicaid patients. Obstetricians surveyed listed low reimbursements, slow payments, denial of eligibility after the patient has been in care, and a belief that Medicaid patients are more likely to sue as reasons for nonparticipation.

In many states the reimbursement rate for total obstetric care is well below half the prevailing charge for obstetric care. In 1986 the ACOG found the median charge for total obstetric care nationwide to be $1,000. For that same year the General Accounting Office (GAO) reported the national average reimbursement rate under Medicaid was $473.11. In some states payment rates have not been updated in more than a decade. For example, for complete obstetric care including all prenatal visits plus attendance

at delivery, the GAO recently reported that New Hampshire reimburses $214, West Virginia $255, and Pennsylvania $312.

Professional liability concerns discourage physician participation in two ways. First, the cost of liability insurance may constitute a large portion or actually exceed the reimbursement rate for obstetric services from Medicaid. In New Hampshire the average cost of liability insurance is $154 per delivery, $273 in West Virginia, and $203 in Pennsylvania. Increasingly, we are noting a decline in access to obstetric services in rural and economically depressed communities as obstetricians, family practitioners, and nurse midwives confronting the reality of high insurance premiums and low reimbursement from public programs give up the practice of obstetrics in those communities. Last year, Danine Rydland, MD, an obstetrician from Petersburg, West Virginia, who testified before the Senate Labor and Human Resources Committee indicated nearly 50 percent of her obstetric patients were either Medicaid or MCH sponsored. Given a Medicaid payment rate in West Virginia of only $255 for total obstetric care, she did not see how she could cover the next liability insurance premium.

Secondly, some obstetricians believe that caring for Medicaid patients results in greater liability exposure. Because Medicaid patients are at greater risk of having a poor obstetrical outcome, they are perceived by obstetricians as more likely to initiate a malpractice suit. The ACOG is currently researching the obstetric suit rate for Medicaid patients as compared to others.

The ACOG supports establishment of a Medicaid demonstration program to find ways to improve access to needed physician services by pregnant women and children. Specifically, states should be encouraged to try innovative approaches to increasing provider participation. These could include:

(1) improving compensation, expediting reimbursement, and using innovative payment mechanisms including global fees for maternity and pediatric services with guaranteed periodic payments;

(2) assisting in securing, or paying for, medical malpratice insurance or otherwise sharing in the risk of liability for medical malpractice;

(3) decreasing unnecessary administrative burdens in submitting claims or securing authorization for treatment;

(4) guaranteeing continuity of coverage, and expediting eligibility determinations; and

(5) covering medical services to meet the needs of high-risk pregnant women and infants.

Both research and anecdotal evidence indicate there is a positive response on the part of physicians in states which have increased reimbursement rates and made improvements in claims processing, eligibility determinations, and scope of services. A demonstration program may well show that it is possible to improve access to prenatal care by Medicaid recipients and ultimately reduce the rate of infant mortality. We urge the Committee to look favorably at the demonstration program contained in Sec. 4104 of the reconciliation bill reported by the House Energy and Commerce Committee.

CONCLUSIONS AND RECOMMENDATIONS

Prenatal care has come a long way since I began practicing. It used to be that prenatal care consisted of little more than monthly checkups employing a scale, a blood pressure cuff, and a tape measure. Modern obstetric care involves such services as ultrasound, amniocentesis, AFP screening, Rhogam, stress and non-stress tests, consultations with medicine and surgery, and hospital care for conditions such as threatened premature labor. High risk women and teens need a comprehensive array of services including nutrition counseling, treatment for drug abuse, smoking cessation, social services, academic and vocational education, psychological counseling, and transportation. At the very minimum, good medical care is essential and dictates that prenatal care always be coordinated with labor and delivery. Unfortunately, it is relatively common for public funds to be made available for prenatal care without the availability of funding for or coordination with labor and delivery. When there is a public or community hospital to provide backup, coordination is good. But where such backup is missing, the beds are unavailable, or the hospital requires a substantial deposit prior to admission, patients are forced to show up at the emergency room of a hospital when they go into labor because no provison has been made for inpatient care. The advantages of the prenatal care are virtually lost if the patient arrives in labor and the delivery attendant has no record of her pregnancy.

In addition to supporting S. 422 to expand Medicaid eligibility and the demonstration program to try innovative methods to increase the availability of services to Medicaid beneficiaries, the College makes the following recommendations:

1. States which fail to enact the OBRA options to increase Medicaid eligibility to 100 percent of poverty and to establish a program of presumptive eligibility must be encouraged to do so. As long as some states set their eligibility criteria for pregnant

women as low as 16 percent of poverty as is now the case, tremendous disparities in the rates at which pregnant women obtain early prenatal care will persist.

2. Congress should increase funding for the Maternal and Child Health Block Grant. Like community health centers, clinics funded through MCH block grant funds, coupled with state and local dollars, are a critically important source of prenatal care for poor women. The block grant is an important resource for states and a source of care for women who would otherwise fall through the cracks because they don't qualify for Medicaid.

3. Congress should increase the cigarette excise tax. Smoking during pregnancy increases the risk of miscarriage, premature delivery, and stillbirth. Newborns of smoking mothers weigh on the average 200 grams less than babies born to mothers who do not smoke. Smoking is thus an important and preventable contributor to low birthweight. Despite the documented health risks to children from maternal smoking during pregnancy, smoking by women in the childbearing years persists. More teenage girls now smoke than boys. The cigarette excise tax is an effective deterrent to smoking. Studies show a 10 percent increase in the cost of cigarettes produces approximately a 4 percent decrease in smoking among adults and a much greater effect -- a 14 percent decrease -- in smoking among teenagers.

4. Congress should maintain the existing Medicaid matching rate for family planning services. Family planning must be an integral part of our national strategy to improve maternal and child health. According to the IOM report, family planning contributes specifically to reductions in low birthweight by reducing the number of births to women with high risk characteristics, increasing the interval between births, and increasing the proportion of pregnancies that are wanted at the time of conception. Women who want to be pregnant are more likely to seek early prenatal care, while women who do not want to be pregnant frequently delay seeking care. We oppose the Administrations's budget proposal to reduce the Medicaid family planning matching rate.

Thank you for this opportunity to testify. I would be happy to respond to any questions you might have.

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TESTIMONY ON

CHILD HEALTH CARE LEGISLATION

Statement of

Robert H. Sweeney

Mr. Chairman, I am Robert H. Sweeney, President of NACHRI -- the National Association of Children's Hospitals and Related Institutions. NACHRI is the only national organization of Children's Hospitals. We represent 91 Children's Hospitals in 36 states plus the District of Columbia.

Our member hospitals are unique institutions. All are non-profit. They are teaching hospitals, and many are engaged in research. Children's Hospitals serve as regional medical centers, receiving referrals from around the country and the world. They provide highly specialized pediatric care that often is otherwise unavailable in the region in which they operate.

I thank you for the opportunity to testify on the legislation pending before the Finance Committee, which would affect the delivery of health care for children.

Children's Hospitals Have Unique Experience in Providing Health Care for Children.

Children's Hospitals specialize in the treatment of serious illnesses and disabilities among children from birth through early adulthood. For example, about 26 percent of the beds in Children's Hospitals are devoted to critical and special care. Among hospitals in general, only about 8 percent of their beds are for such intensive care.

Children's Hospitals serve a large population of children and their families. They care for one out of every 12 children

hospitalized in the U.S. each year -- more than 400,000 annually. And while they are best known for their inpatient care, Children's Hospitals provide an unusually high volume of outpatient specialty care and primary health care. For example, on average, Children's Hospitals provide approximately twice the volume of outpatient visits per admission as do acute care community hospitals.

Because of their specialization and the size of the population they serve, Children's Hospitals employ nearly 60,000 people and incur more than $2.4 billion in expenses each year.

Children's Hospitals Have Unique Experience in Providing Care for the Poor, Both Medicaid Beneficiaries and the Uninsured.

About 33 percent of Children's Hospitals' patient activity involves the care of children from low income families -- both Medicaid patients and patients whose families are unable to pay.

About 26 percent of Children's Hospitals' patient activity involves Medicaid beneficiaries. In some instances, Medicaid can account for more than 50 percent of the income of a Children's Hospital.

Because Children's Hospitals work so extensively with children of low income families, we can speak from first-hand experience for the validity of data that tell us:

- 20 percent of all children are uninsured or underinsured, and 67 percent of uninsured children have at least one employed parent or guardian;

- over 25 percent of all children and 40 percent of the uninsured have no physician visits in a year;

- 63 percent of pregnant women who are either Medicaid eligible or uninsured receive no prenatal care or receive it late, despite the fact that early prenatal care is a significant factor in reducing premature births.

- Although the number of children in poverty increased 29 percent between fiscal year 1978 and 1985, the number of children served under Medicaid dropped 4 percent.

Children's Hospitals Are Acutely Aware of the Catastrophic Health Care Costs Confronting Young Families.

Because of their special experience with both high cost pediatric care and children of low-income families, Children's Hospitals recognize that the problem of catastrophic health care costs for children is multi-faceted. Depending on the individual family, acute care, chronic care, or even primary care costs can be catastrophic. They literally can jeopardize the financial survival of the family. For example:

- For the low income family, the cost of even routine medical care can be catastrophic. Children of poor families are twice as likely to have no regular source of primary health care as non-poor children. In fact, in many communities, Children's Hospitals have become the only source of primary care for low income children.

- Over the course of several years, the accumulative costs of care for the chronically ill or disabled can be catastrophic. For example, children with ongoing, chronic care needs can incur annual costs of anywhere from a few thousand dollars to as much as $350,000 for a child suffering from a severe lung problem who is ventilator dependent.

- Finally, there are the costs we most typically think of as catastrophic -- the extremely high costs that accompany an extraordinary episode of illness or disability. For example, approximately 220,000 premature babies are born each year. Each incurs average expenses of more than $35,000 annually. For many, the costs reach $100,000 or more.

The Problem of Children's Health Care Costs Requires a Multi-faceted Approach.

Because it involves families of different income levels, and because it involves different kinds of health care problems, the problem of health care costs for children demands a multi-faceted approach. It must ensure the following:

- access to preventive health care, particularly for pregnant women and young children;

- access to public and private health insurance to cover a broad range of acute and chronic health care needs;

- government insurance of last resort to protect both insured and uninsured families from costs that exceed their insurance and jeopardize their financial stability.

There are several immediate steps the Committee can take to begin to address the problems of children's health care. By acting on pending legislation the Committee can build on the existing health care financing system -- to contain the erosion of children's access to health care we have witnessed in recent years and to fill in the most obvious gaps. Certainly there are other approaches the Committee could take, but together the pending proposals represent an immediately effective package.

Looking beyond the reconciliation markup, the Committee also should take steps to re-examine the underlying financing system itself -- particularly the organization and purposes of Medicaid.

The Finance Committee Should Act Now to Expand Access to Medicaid Coverage and Enact Catastrophic Legislation for Children in 1987 and 1988.

Finance Committee members' legislative leadership this year demonstrates awareness of the breadth of legislation required to deal with the health care needs of children.

- Sen. Bradley's S. 422 builds on the Committee's commitment to expand Medicaid eligibility for pregnant women and young children.

- Sen. Chafee's MedAmerica, S. 1139, offers the opportunity for the near-poor to buy into Medicaid with subsidized premiums.

- Sen. Chafee's catastrophic bill, S. 1537, creates a safety net to protect families from the most extreme cases. About 3.6 million children are born each year. Nearly 10,000 families have newborns and children under age 1 whose medical expenses exceed $50,000, and the out-of-pocket liability is greater than 10 percent of adjusted gross income or $10,000. The care for each of these 10,000 children averages about $90,000.

- Sen. Durenberger's new bill, S. 1740, encourages states to expand Medicaid eligibility for children with chronic illness or disability.

NACHRI supports each of these bills. In particular, we have worked closely with a coalition of organizations on Sen.

Chafee's S. 1537, and we applaud his special leadership in calling attention to the needs of families facing very high health care bills. Together, these four bills represent a legislative package that would contain the problem of catastrophic health cost and begin to fill in the gaps we see in our financing system for children's health care.

However, we also understand the budgetary pressures facing the Committee. Congress' budget resolution simply does not accommodate most of the budget outlays these bills together would require. Therefore, NACHRI offers the following recommendations for Committee action during the upcoming reconciliation markup:

- Adopt S. 422 in full. It is a modest but critical step toward preventing future catastrophic cases, and it is fully covered by the budget resolution.

- Enact -- within the next year -- legislation to cover the very high cost catastrophic cases targeted by S. 1537. To lay the groundwork for that action, use the reconciliation bill to direct either the GAO or the OTA to produce studies, within the next six months, that document the children's catastrophic problem, both for acute care and chronic cases.

- Support Sen. Bentsen's proposal for the establishment of a Commission on Children, S. 1711.

- Should additional funding prove to be available within the Committee's 302(b) allocation, look to expand the mandates for additional Medicaid coverage under S. 422. The Committee also could consider the possibility of phasing-in Medicaid buy-ins, either on a demonstration basis or by targeting them for individuals with chronic illness or disability along the lines of Sen. Durenberger's proposal.

The Finance Committee Should Undertake a Thorough Evaluation and Reform of Medicaid.

Our recommendations for the above measures respond to the most immediate health care needs of children. They will protect individual families today. However, there are fundamental problems in the underlying health care financing system that in theory should benefit all children equitably, but in fact falls far short of that goal.

Although it is the major program for child health care across the country, Medicaid provides inadequate coverage for children. In 1985, when children under age 18 accounted for 20 percent of the poverty population, they accounted for only 14 percent of Medicaid expenditures.

In addition, Medicaid is a very inconsistent program in its eligibility and coverage requirements. For example, in 1984, eligibility income in Alabama was 17 percent of the federal poverty level of $10,200 for a family of four; in California it was 74 percent. Overall, average eligibility was only 38 percent of the poverty level. States also vary substantially in the coverage their Medicaid programs provide in terms of numbers of inpatient hospital days, outpatient visits, and procedures.

Because of Children's Hospitals' extensive experience in caring for low-income children, we are convinced the time has come to reassess Medicaid in terms of the adequacy of children's eligibility for coverage, the extent of their coverage, and the reimbursement of the coverage.

Such evaluation should address the following questions:

- Should Medicaid eligibility be uncoupled from welfare eligiblity?

- Should minimum federal standards be set for eligiblity, coverage, and reimbursement rates to ensure more equal access to care for children, regardless of the state or region in which they live?

- Should public insurance for children be split off entirely from Medicaid, since it is increasingly devoted to the long-term care costs of the elderly? Medicaid was first enacted at the same time as Medicare, and it reflects Medicare's episodic orientation toward health care coverage. However, children require a continuum of care. There have been attempts to address this need, such as the creation of EPSDT. But these should be comprehensive assessment of the adequacy of Medicaid's coverage of the needs of children, distinct from the elderly.

- How should we re-define the private as well as public sector responsibilities for the health care insurance of our children? More than 11 million children are uninsured despite the fact they have at least one employed parent. At a minimum, we should expect our private health care financing system to provide basic and catastrophic care for the families of the employed. We hope the Committee will explore ways in which federal tax policy can be revised to encourage broader private sector responsiblity for children's health care insurance.

Mr. Chairman, I want to say again how much I appreciate the opportunity to testify before you. I would be happy to answer any questions the Committee may have or to provide additional material for the record.

Testimony of The
Association of Maternal and Child Health Programs
Before the Senate Finance Subcommittee
on Health
on

The Maternal and Child Health Block Grant
and Other Matters Pending

Presented by:

William H. Hollinshead, III, M.D., M.P.H.

Mr. Chairman and Distinguished Members of this Subcommittee:

The Association of Maternal and Child Health Programs (AMCHP) is pleased to have this opportunity to present testimony concerning the catastrophic care, Medicaid and infant mortality initiatives before the Congress. The members of AMCHP are the Directors of State and Territorial Maternal and Child Health Programs. The MCH Directors manage Title V programs and coordinate with other health, social service and educational programs to improve the health and well-being of children and parents. Leadership for the Association is provided by four Officers and ten Councillors who are representative of the State MCH Directors from all regions of the country.

There are several proposals now before this Committee that the Association urges you to adopt. Before discussing these needed reforms, however, allow us briefly to describe the current situation from the perspective of MCH Directors. Simply stated, despite our efforts and those of our colleagues, America is not the safest or healthiest place to be born or brought up in the 1980's.

We have insufficient or incomplete prenatal care for many of our highest risk mothers. We have far too many babies born too early or too small. We have death and disease rates in early childhood that are much too high. We have an excessive number of unwanted pregnancies, especially among teens. We do not have the proper vehicle to promote health care, safety, and long-term

healthy lifestyles for children through day care, the schools, and other community resources accessible to young families. Moreover, most of these problems are magnified for families raising children who have special health care needs.

Many of these problems stem from a basic lack of social policy. We stand alone among the developed democracies in our lack of a coherent family support policy or program, and in our incomplete, inconsistent, incoherent, and increasingly unaffordable arrangements for medical care.

Our Association believes that every child should be assured of access to basic medical services, to preventive services that will protect children's health and development, to specialized services as needed for catastrophic or chronic health problems, and to family support services that will allow parents to do those things that only parents can do well for their children. Our Association also knows from many years of public health experience that special health risks and health needs often require the special effort of care coordination, parent support, and child advocacy that is sometimes called Case Management. Financial coverage for services is needed, but a professional friend is what makes basic coverage into a successful program of care for a family.

State MCH agencies have a mandate to study and report on the health of children. There is a growing set of state reports on infant mortality, low birthweight, access to care, family support services, pediatric chronic illness, and other important child health problems. We also have a unique mandate to work with all segments of the health care system. In Utah, we worked out a new and much more effective arrangement between Maternal and Child Health, Medicaid, and Health Maintenance Organizations. In Arkansas, Maternal and Child Health and Medicaid have worked closely to implement presumptive eligibility reforms thereby

extending coverage to many families in need, and expanding the services available.

Title V maternal and child health agencies have a special responsibility to ensure health services for the poor, the poorly educated, minorities, and families with poor access to health care due to poverty, cultural barriers, and geographical isolation. We have a long history of programs for families facing the challenge of raising children with serious chronic or disabling disease.

Despite the recent gaps in human service programs, there has been progress in a few areas, and we have patched many of the holes in care. In primary care, we have encouraged new options for Medicaid coverage of the poor--options which are now being adopted by many states to improve coverage of both mothers and children. But Medicaid still does not include a large proportion of low income families with no insurance, and so a growing number of states have developed and funded state prenatal care coverage plans to fill part of this remaining gap.

Title V agencies have also pioneered a variety of initiatives to strengthen community clinics and improve programs for school age children, often working jointly with state chapters of the American Academy of Pediatrics. These efforts are strengthened by the appropriation of new funds to implement last year's amendments to the Title V authorization which places special emphasis on primary care activities.

The Title V Directors are uniquely equipped to meet the challenges of caring for chronically ill children. The long-term human and financial benefits of family-centered, community based approaches to the care of children who might otherwise live in institutions has been a strong theme in maternal and child health of the 1980's. Nearly every state has undertaken substantial new efforts in family support services, case management, and comprehensive care through its Title V agencies. These efforts will be strengthened with the recent increase in Title V

appropriations. Title V agencies are also at the heart of making expanded early intervention and education for the handicapped programs work for young families with children at biological or environmental risk.

What are the common themes we see in many states' recent experience? First, health care coverage is weakest for young families with children. Many eligible families are not enrolled in Medicaid, and most low income families are still not eligible. Our current system does not cover a lot of the services that make the most difference to positive outcomes--education, family support, respite, and home care services. Current reimbursement levels also do not meet costs, especially for preventive services. We can confirm that very few providers get rich caring for young families. Even fewer find much financial reward in caring for poor children.

One promising step towards addressing these issues is the recent creation of the National Commission to Prevent Infant Mortality. I appreciate the opportunity to serve with such distinguished members as Senator Lawton Chiles (the Commission Chairman), Senator David Durenberger, Dr. Otis Bowen, Secretary of HHS, other representatives of federal and state governments, and notable maternal and child health experts.

Established on July 1 of this year, the Commission has been charged by Congress with putting together a national strategy for reducing and preventing infant mortality in this country, and a report to Congress and the President is due within one year. To accomplish its work, the Commission will be holding public hearings around the country to bring the problem and proposed solutions to the attention of public policymakers and private sector leaders. We will place emphasis on proposed solutions because even though we do not have all the answers, we do know a good deal about what causes infants to die and what can be done to prevent many of these deaths. If a mother receives comprehensive,

high quality prenatal care, started early in her pregnancy, she has a much better chance of having a healthy baby than if she gets late or no prenatal care.

The Commission will hold hearings on the role of the community, the role of the media, and the role of federal and state governments in reducing infant mortality, as well as a hearing on international comparisons. The Commission will also be analyzing recommendations that have been made in numerous national and regional studies and reports, and hopes to spotlight the most effective programs that our states and localities are offering.

Turning now to immediate solutions, there are a variety of legislative proposals pending which the Association strongly endorses as short-term improvements to a global problem.

Catastrophic Care

The term "catastrophic" in the health care field is relative. Any medical bill is catastrophic to a family who cannot afford to pay for a normal office visit. Providing adequate insurance to encourage comprehensive care for all children is the long-range solution. However, one problem demanding immediate attention is the lack of protection for those uninsured families with children who have incurred substantial medical expenses.

On July 23, 1987, Senator Chafee introduced S. 1537. This legislation would authorize a total of $500 million to be placed into a children's catastrophic fund, of which $375 million would be available to relieve families with an infant who has accumulated more than $50,000 in medical bills during the first year of life. The remaining $125 million would help support the provision by Title V programs of care management for any child with anticipated annual medical expenses exceeding $5,000.

Medicaid Reforms

Since its inception in 1965, Medicaid has extended health coverage primarily to families who receive AFDC or SSI. Reforms recently enacted in the Consolidated Omnibus Budget Reconciliation

Act (COBRA) and the Sixth Omnibus Budget Reconciliation Act (SOBRA) have provided Medicaid coverage to many low income women and children who lacked medical insurance before, but further reforms are needed.

S.422 - Medicaid Infant Mortality Amendments

This bill, introduced by Senator Bradley on January 29, 1987, would provide Medicaid benefits to poor children and pregnant women between 100% and 185% of poverty. This legislation would additionally mandate those states that do not already do so to extend Medicaid coverage to children ages 6, 7, and 8 on a year-by-year basis for those children whose family incomes do not exceed AFDC standards. It also gives states the option of accelerating the currently existing year-by-year phase-in of children up to age 5 whose family incomes are between AFDC standards and the Federal poverty level. Finally, S.422 would give states the option of covering these children on a year-by-year basis up to age 5.

S.1139 - Med America Act

This legislation, introduced by Senator Chafee on May 6, 1987, would expand Medicaid coverage in the following ways:

1) It would sever Medicaid from cash benefits programs such as AFDC and SSI. The States would be given the option of providing Medicaid benefits to anyone with an income falling below the Federal poverty level, regardless of whether (s)he qualifies for AFDC or SSI programs;

2) States would be given the option of allowing persons with incomes at or near the Federal poverty level to purchase health insurance through Medicaid;

3) States would be able to allow persons whose family incomes and resources are in excess of 200% of the Federal poverty level to purchase Medicaid benefits for a non-income adjusted premium if they have been excluded from private health insurance because of a medical impairment or disability.

In closing, we wish the Committee to note that, in implementing these reforms and our Title V mandate more generally, we the MCH directors will stand firmly by the following principles:

1. These programs must each have a conscious investment in outreach and marketing to the target families, and an investment in education of those families, both as consumers, and as care givers.
2. Maternal and child health agencies will continue to work with our medical colleagues of the Academy and the College, and with others to be sure that good standards of care are developed and enforced in these programs. It is particularly difficult to assure adequate quality of services in inadequately funded programs. We will develop explicit mandates to the state health departments to establish and monitor appropriate standards of care.
3. As with any important investment, performance is the final measure of effective health programs. We believe the public and Congress deserve a careful accounting for these initiatives. We will, therefore, evaluate these programs promptly and candidly.
4. Care coordination, sometimes called Case Management, is often the decisive factor in making new coverage work. Working with physicians and a variety of other colleagues, State maternal and child health agencies have been participating in the coordination of care for children and young families for many

years. Care coordination is critical for families with special needs children. It has proven equally important in assuring good prenatal care to high risk mothers. We believe that care coordination must be done for the sake of better care and better outcome--not always for short-term cost containment. Therefore we endorse current proposals which make care coordination a reimbursable benefit. Title V agencies consider care coordination to be one of their most important responsibilities.

Thank you for giving the Association the opportunity to testify.

NATIONAL ASSOCIATION of COUNTIES

BARBARA SHIPNUCK'S TESTIMONY

BEFORE THE SENATE FINANCE HEALTH SUBCOMMITTEE

ON CHILD HEALTH PROGRAMS

STATEMENT OF BARBARA SHIPNUCK, SUPERVISOR, MONTEREY COUNTY, CALIFORNIA, BEFORE THE SENATE FINANCE HEALTH SUBCOMMITTEE, WASHINGTON, D.C., OCTOBER 2, 1987.

MR. CHAIRMAN, MEMBERS OF THE SUBCOMMITTEE, MY NAME IS BARBARA SHIPNUCK AND I AM PLEASED TO BE HERE TODAY TO PRESENT TESTIMONY REGARDING CHILDREN'S HEALTH ON BEHALF OF THE NATIONAL ASSOCIATION OF COUNTIES (NACo)*. I AM A COUNTY SUPERVISOR OF MONTEREY COUNTY, CALIFORNIA AND THE CHAIR OF NACo'S HEALTH AND EDUCATION STEERING COMMITTEE'S SUBCOMMITTEE ON HEALTH.

I UNDERSTAND THAT YOUR FOCUS IS ON THE MEDICAID PROGRAM AND THE MATERNAL AND CHILD HEALTH BLOCK GRANT, SOCIAL SECURITY PROGRAMS UNDER THE JURISDICTION OF THE FINANCE COMMITTEE, AND ON PROPOSALS INTRODUCED BY SUBCOMMITTEE MEMBERS SENATORS BRADLEY, CHAFEE, AND DURENBERGER.

WE WILL LEAVE TO OTHER EXPERTS THE HEALTH STATUS AND NEEDS OF CHILDREN AND WILL FOCUS ON THE COUNTY'S ROLE AS SERVICE PROVIDER TO THIS GROUP. COUNTIES PROVIDE THE SOCIAL AND HEALTH CARE SAFETY NET FOR OUR NATION AND IN THE MAJORITY OF STATES COUNTIES HAVE A LEGAL RESPONSIBILITY TO PROVIDE SERVICES TO INDIGENT FAMILIES, INCLUDING CHILDREN.

COUNTIES ARE "WHERE THE RUBBER MEETS THE ROAD" FOR THOUSANDS OF PERSONS UNABLE TO AFFORD HEALTH CARE SERVICES. THEREFORE, LET ME ASSURE YOU OF NACo'S COMMITMENT AND PRIORITY

FOR DELIVERING QUALITY HEALTH CARE SERVICES TO OUR NATION'S WOMEN AND YOUTH TARGETED IN THESE PROGRAMS AND OUR SINCERE WILLINGNESS TO WORK WITH YOU AND THIS SUBCOMMITTEE ON THAT ISSUE.

NACo'S POLICY POSITION ON THIS ISSUE IS CLEAR AND WE HAVE IN OUR COUNTY PLATFORM SEVERAL RESOLUTIONS REGARDING THE NEED FOR ATTENTION TO NEONATAL CARE, HEALTH CARE FOR HIGH RISK GROUPS SUCH AS PREGNANT WOMEN AND CHILDREN, AND THE NEED FOR LOCAL INVOLVEMENT IN BLOCK GRANT IMPLEMENTATION, INTERGOVERNMENTAL COOPERATION IN ASSURING THAT HEALTH AND MENTAL HEALTH SERVICES ARE PROVIDED TO THOSE IN NEED.

IN PREPARING THIS TESTIMONY, WE SPOKE WITH COUNTY OFFICIALS IN SEVERAL STATES, CALIFORNIA, MONTANA, MINNESOTA, NEW YORK, AND NORTH CAROLINA. WE TARGETED STATES WHERE COUNTIES CONTRIBUTE DIRECTLY TO THE STATE MEDICAID MATCH, OR WHERE COUNTY HEALTH DEPARTMENTS HAVE STRONG PROGRAMS FOR CHILDREN'S SERVICES.

WE WOULD LIKE TO SHARE WITH YOU AN UNDERSTANDING OF

1) THE COUNTY ROLE IN HEALTH CARE SERVICE PROVISION;

2) COUNTY EXPERIENCE WITH MEDICAID AND MATERNAL CHILD HEALTH SERVICE SUPPORT, ESPECIALLY EXPANDED MEDICAID ELIGIBILITY OPTIONS; AND

3) OTHER ISSUES OF CONCERN IN THE AREA OF CHILDREN'S HEALTH CARE SERVICES INCLUDING CATASTROPHIC COST PROTECTION.

IN FACT, WE ARE NOW WORKING ON A SURVEY OF THE ACTIVITIES AND PRIMARY FUNDING SOURCES OF COUNTY HEALTH DEPARTMENTS. WE ARE INCLUDING CHILDREN'S HEALTH CARE SERVICES AS ONE OF THE MAJOR CATEGORIES TO BE IDENTIFIED. WE WILL BE GLAD TO SHARE THIS INFORMATION WITH THE SUBCOMMITTEE WHEN IT IS AVAILABLE.

<u>COUNTY ROLE IN HEALTH CARE</u>

THE NATION'S 3,106 COUNTIES OPERATE NEARLY 1,600 COUNTY HEALTH DEPARTMENTS, WHICH FUND AND PROVIDE BASIC HEALTH CARE

SERVICES. MATERNAL AND CHILD HEALTH SERVICES ARE PROVIDED BY 89 PERCENT, AND NEARLY HALF ARE THE SOLE PROVIDER OF SUCH SERVICES IN THEIR AREA.

COUNTIES COMBINE THIS SERVICE PROVISION ROLE WITH A SIGNIFICANT TRAINING AND TEACHING FUNCTION THAT IS OFTEN OVERLOOKED. THERE ARE 900 COUNTY HOSPITALS IN THE COUNTRY, NEARLY HALF OF ALL THE NATION'S PUBLIC HOSPITALS. THIRTY-ONE COUNTY HOSPITALS ARE MEMBERS OF THE AMERICAN ASSOCIATION OF MEDICAL SCHOOLS COUNCIL OF TEACHING HOSPITALS, AFFILIATED WITH SOME OF OUR NATION'S FINEST MEDICAL SCHOOLS.

IN FY 85, EXCLUDING THE DOZEN OR SO LARGE CONSOLIDATED CITY/COUNTY MUNICIPALITIES, COUNTIES SPENT CLOSE TO $20 BILLION ON HEALTH CARE. COUNTY HEALTH DEPARTMENTS AND CLINICS ACCOUNTED FOR $4.8 BILLION, HOSPITALS FOR $9.0 BILLION. MEDICAL VENDOR PAYMENTS WERE OVER $500 MILLION, AND A SIGNIFICANT PROPORTION OF THE $5.9 BILLION SPENT FOR "OTHER PUBLIC WELFARE" SUPPORTED COUNTY HEALTH FACILITIES OR NURSING HOMES.

COUNTIES, AS YOU KNOW, ARE STATE-CREATED ENTITIES. THEIR FUNCTIONS, AS WELL AS THE ABILITY TO GENERATE RESOURCES TO PAY FOR THEM, ARE PRESCRIBED BY THE STATE. THE ABILITY TO LEVY TAXES IN GENERAL IS A STATE AUTHORIZED FUNCTION AND TWENTY-SIX STATES IMPOSE SOME FORM OF TAXING LIMITATION ON COUNTIES. THE PRIMARY LOCAL REVENUE SOURCE FOR COUNTIES IS THE PROPERTY TAX. POLLS CONDUCTED BY THE U.S. ADVISORY COMMISSION ON INTERGOVERNMENTAL RELATIONS (ACIR) CLEARLY SHOW THAT PROPERTY TAXES ARE THE SINGLE MOST UNPOPULAR TAX. IN RECENT YEARS, VARIOUS FORMS OF TAXPAYER REVOLT HAS MEANT THAT PROPERTY TAXES IN PARTICULAR, AND THEREFORE LOCAL REVENUES IN GENERAL, HAVE BEEN SEVERELY CONSTRAINED.

BECAUSE OF THE RISING COSTS OF PROVIDING HEALTH CARE SERVICES AND LIMITATIONS ON REVENUE SOURCES AND AVAILABLE FUNDS TO PAY FOR THEM WITH, COUNTIES OVER THE PAST DECADE TURNED INCREASINGLY TO OTHER GENERAL REVENUE SOURCES. IT SHOULD COME AS NO SURPRISE TO THE MEMBERS OF THIS SUBCOMMITTEE THAT THE ELIMINATION OF GENERAL REVENUE SHARING FUNDS DEPRIVED COUNTIES OF SIGNIFICANT AID IN MEETING THESE REVENUE GAPS. LOS ANGELES COUNTY, FOR EXAMPLE, HAD USED THEIR ENTIRE $80 MILLION REVENUE SHARING ALLOCATION IN 1984 TO SUPPORT INDIGENT HEALTH CARE SERVICES.

COUNTIES AND MEDICAID:

I WILL FOCUS NOW ON COUNTY EXPERIENCES WITH THE MEDICAID PROGRAM. TO A PERSON, THE OFFICIALS WITH WHOM WE SPOKE SUPPORTED EXPANDED MEDICAID ELIGIBILITY. THIS WAS TRUE FOR THE OPTIONAL PROVISIONS ALLOWED LAST YEAR. I CAN GUARANTEE SIMILAR POSITIVE RECEPTION TO THE GREATER FLEXIBILITY ALLOWED IN THE PROPOSALS OF SENATORS BRADLEY & DURENBERGER.

CALIFORNIA:

UNFORTUNATELY, I MUST REPORT THAT CALIFORNIA'S GOVERNOR VETOED A BILL TO ADOPT THE OPTIONAL EXPANDED MEDICAID ELIGIBILITY LEVELS. THIS IS PARTICULARLY UNFORTUNATE FOR MY COUNTY OF MONTEREY. WE HAVE A POPULATION OF 330,000 YET RUN A $340,000 PRENATAL CARE PROGRAM, CLEAR EVIDENCE OF GREAT NEED FOR THESE SERVICES. THE SUBCOMMITTEE MAY BE INTERESTED TO KNOW THAT MONTEREY HAS THE NEXT HIGHEST RATE OF ILLEGAL ALIENS IN THE STATE NEXT TO LOS ANGELES COUNTY. THE MAJORITY OF THE PREGNANT WOMEN OF THIS GROUP ARE CONSIDERED HIGH RISK. PREGNANT WOMEN WHO ARE ILLEGAL ALIENS ARE ELIGIBLE FOR MEDICAID UNDER A RECENT BUDGET ACT; CERTAINLY AFTER BIRTH, THE BABIES THEMSELVES ARE ELIGIBLE FOR MEDICAID.

I HOPE THE FURTHER EXPANSION ALLOWED BY SENATOR BRADLEY'S BILL, AND THE ENCOURAGEMENT OFFERED BY SENATOR DURENBERGER'S BILL WILL ENCOURAGE OUR GOVERNOR TO RETHINK HIS POSITION ON THIS ISSUE.

NORTH CAROLINA:

IN NORTH CAROLINA AN ADDITIONAL 16,000 PREGNANT WOMEN AND 23,000 CHILDREN UNDER THE AGE OF 2 WILL BECOME ELIGIBLE UNDER LEGISLATION INSPIRED BY THE OPTION MADE AVAILABLE LAST YEAR. THIS IS A SIGNIFICANT IMPROVEMENT IN THE NUMBERS OF LOW INCOME PREGNANT WOMEN AND CHILDREN WHO WILL BE SERVED BY MEDICAID. FOR THIS EXPANDED SERVICE CAPACITY, EFFECTIVE OCTOBER 1, 1987, COUNTIES WILL CONTRIBUTE $1.9 MILLION. THIS WILL BE PART OF THE TOTAL STATE MATCH OF $11.5 MILLION, IN ORDER TO RECEIVE $23.4 MILLION FEDERAL DOLLARS.

NORTH CAROLINA HAS ALSO ADOPTED THE PRESUMPTIVE ELIGIBILITY OPTION. OFFICIALS WITH WHOM WE SPOKE FELT IT ESPECIALLY VALUABLE THAT SCREENING FOR THIS COULD BE DONE DIRECTLY AT COUNTY HEALTH CLINICS, INSTEAD OF SOCIAL SERVICE DEPARTMENT PROCESSING. IN THIS WAY PREGNANT WOMEN CAN IMMEDIATELY GET NECESSARY AND SOMETIMES CRUCIAL SERVICES.

MINNESOTA:

IN MINNESOTA, THE LEGISLATURE LIKEWISE HAS INCREASED THE INCOME ELIGIBILITY THRESHOLD TO 133% OF THE AFDC LEVEL, ROUGHLY EQUIVALENT TO THE FEDERAL POVERTY LEVEL. MEDICALLY NEEDY CHILDREN UP TO THE AGE OF 21 ARE ALREADY COVERED. THE COUNTY SHARE OF THE STATE MEDICAID MATCH IS 10%, OR 4.63 PERCENT OF TOTAL MEDICAID FUNDS. THUS, THE EXPANDED ELIGIBILITY WILL BE SUPPORTED DURING THE PHASE-IN YEAR BY $400,000 COUNTY DOLLARS. WHEN FULLY IMPLEMENTED, COUNTIES WILL CONTRIBUTE NEARLY A MILLION DOLLARS TO ALLOW AN ADDITIONAL 11,500 NEEDY CHILDREN AND 8,700

AFDC RELATED FAMILIES ELIGIBILITY FOR MEDICAID ASSISTANCE. (THESE FIGURES WILL BE REDUCED SOMEWHAT BECAUSE OF A CHANGE IN EARNED INCOME CALCULATION).

THE SOCIAL SERVICE DIRECTOR IN CASS COUNTY, IN CENTRAL MINNESOTA, WAS VERY ENTHUSIASTIC ABOUT THIS EXPANDED SERVICE AVAILABILITY. HE NOTED THAT THE MEDIAN FAMILY INCOME IN HIS COUNTY IS $15,000 PER YEAR, MANY PERSONS CANNOT AFFORD HEALTH INSURANCE OR WORK FOR EMPLOYERS WHO DO NOT PROVIDE IT. THE AVERAGE NUMBER OF CHILDREN PER FAMILY IN CASS COUNTY IS THREE OR MORE.

THESE COUNTY OFFICIALS RECOGNIZE THAT INCREASED ELIGIBILITY MEANS INCREASED TOTAL COSTS AND GREATER TOTAL CONTRIBUTION FROM COUNTIES. COUNTIES ARE COMMITTED TO THE WELL-BEING OF THEIR YOUTH AND RECOGNIZE THE WISDOM OF SUCH COOPERATIVE INTERGOVERNMENTAL PROGRAMS.

COUNTIES AND THE MATERNAL & CHILD HEALTH BLOCK GRANT

THE USE OF MATERNAL AND CHILD HEALTH BLOCK GRANT MONIES BY COUNTIES PROVIDES MORE INFORMATION ABOUT THE LOCAL LEVEL IMPACT OF FEDERAL SERVICE DOLLARS. THE COUNTIES WE CONTACTED WERE FROM STATES WITH STRONG COUNTY GOVERNMENT AND THEREFORE HAVE ESTABLISHED STRONG COUNTY HEALTH DEPARTMENTS. THIS IS THE CASE FOR THE MAJORITY OF STATES IN THE COUNTRY, WITH THE EXCEPTION OF THE NEW ENGLAND AREA. WE MENTION THIS BECAUSE COUNTY HEALTH DEPARTMENTS ARE THE MOST LOGICAL LOCAL LEVEL SERVICE PROVIDER THROUGH WHICH TO CHANNEL FEDERAL HEALTH SERVICE DOLLARS. ALTHOUGH THEORETICALLY THE BLOCK GRANT ALLOWS STATES MORE FLEXIBILITY, THIS SAME FLEXIBILITY IS NOT ALWAYS DELEGATED TO THE LOCAL LEVEL. THIS SOMETIMES HAMPERS LOCAL LEVEL ABILITY TO TARGET MOST EFFICIENTLY, AND IS OF CONSIDERABLE CONCERN TO LOCAL OFFICIALS. IN SOME CASES, STATE STATUTE STIPULATES THAT COUNTY

HEALTH DEPARTMENTS WILL PROVIDE SERVICES OR ADMINISTER PROGRAMS FUNDED IN WHOLE OR IN PART BY FEDERAL DOLLARS. IN SOME CASES, CONTRACTS ARE NEGOTIATED BY COUNTY HEALTH OFFICERS WITH THE STATE.

EVEN BEFORE THE ADVENT OF FEDERAL BLOCK GRANTS, MINNESOTA ESTABLISHED ITS OWN COMMUNITY HEALTH SERVICES PROGRAM. THIS PROGRAM BLOCK GRANTED TO THE COUNTIES NUMEROUS PUBLIC HEALTH FUNCTIONS. PROGRAMS FOR LOW-BIRTH WEIGHT BABIES, HIGH-RISK MOTHERS, AND CHILDREN AND MOTHERS ON AFDC WERE ESTABLISHED.

WHEN THE FEDERAL MATERNAL AND CHILD HEALTH BLOCK GRANT WAS FIRST ESTABLISHED, HOWEVER THE MONIES DID NOT MOVE BEYOND THE STATE LEVEL. COUNTIES JOINED IN A COALITION TO INSIST ON MAKING THE BLOCK GRANT FUNDS AVAILABLE FOR SERVICES. THE RESULTING COMPROMISE IS THAT ONE THIRD OF THE FEDERAL BLOCK GRANT, OR THIS YEAR SOME $2.5-3 MILLION, IS USED BY MINNESOTA COUNTIES FOR SERVICES TO MOTHERS AND CHILDREN.

SOME COUNTIES ARE ABLE TO SUPPLEMENT THIS, ALTHOUGH THE CAPACITY TO DO SO VARIES. HENNEPIN COUNTY (MINNEAPOLIS) ADDS AN ADDITIONAL $800,000 TO RESULT IN $1.2 MILLION SUPPORT FOR MATERNAL AND CHILD HEALTH SERVICES.

IN LIKE MANNER, HENNEPIN USES SOME OF THIS MONEY TO FUND LOCAL PROGRAMS WHERE IT ACTS AS A STIMULUS TO ATTRACT OTHER PRIVATE SUPPORT. SOME 18-20% OF HENNEPIN'S MATERNAL CHILD HEALTH MONEY IS USED IN THIS WAY TO LEVERAGE BROADER COMMUNITY ACTIVITY.

IN CALIFORNIA, COUNTIES DO NOT GET A LARGE AMOUNT OF MONEY FROM THE MATERNAL AND CHILD HEALTH BLOCK GRANT. IN MONTEREY COUNTY, FOR EXAMPLE, $16,000 IS A SMALL SUPPLEMENT TO OTHER FUNDING FOR NEONATAL CARE PROGRAMS.

MONTANA COUNTIES USES MATERNAL AND CHILD HEALTH MONEY BLOCK GRANT MONEY IN TWO WAYS. A LITTLE LESS THAN HALF COMES DIRECTLY FROM THE STATE TO FUND ANNUAL CONTRACTS WITH COUNTY COMMISSIONERS FOR MATERNAL AND CHILD HEALTH RELATED PROGRAMS. COUNTIES CAN ALSO USE THESE MONIES TO CONTRACT WITH NEIGHBORING COUNTIES. SUCH ADMINISTRATIVE FLEXIBILITY THAT IS ESPECIALLY VALUABLE IN RURAL AREAS. WE WOULD LIKE TO SEE CONGRESS PROMOTE MORE FLEXIBILITY LIKE THIS.

THE REMAINDER OF THE BLOCK GRANT IN MONTANA GOES TO A PROGRAM FOR HANDICAPPED CHILDREN WHICH BRINGS US TO OUR LAST TOPIC, PROPOSALS TO COVER CATASTROPHIC COSTS INCURRED BY CHILDREN'S HEALTH CARE. WE FIND SENATOR CHAFEE'S PROPOSAL AN ENCOURAGING INDICATION OF WILLINGNESS TO ADDRESS THIS COMPLEX AND SERIOUS PROBLEM.

CATASTROPHIC COST PROTECTION

THERE CAN BE NO GREATER JOY THAN TO USE OUR ADVANCED MEDICAL TECHNOLOGY TO CURE DISEASE AND SAVE THE LIFE OF A CHILD. NOR ANY GREATER TRAGEDY THAN TO BE HELPLESS AND UNABLE TO RESPOND BECAUSE OF THE HIGH COSTS OF SUCH CARE. HARD CHOICES UNDERLIE THE REALITY OF THE HIGH COSTS OF INTENSIVE MEDICAL CARE.

NUMEROUS STATES HAVE ADDITIONAL HEALTH CARE PROGRAMS FOR CHILDREN THAT OFFER VALUABLE LESSONS AT THE NATIONAL LEVEL. ORIGINALLY THESE PROGRAMS WERE FOCUSED ON CARE FOR CRIPPLED OR HANDICAPPED CHILDREN BUT THEY HAVE EVOLVED TO SOME EXTENT INTO HEALTH CARE ASSURANCE PROGRAMS.

THE COUNTIES WE CONTACTED PARTICIPATED IN THESE PROGRAMS TO VARYING DEGREES. THIS RANGED FROM NO COUNTY CONTRIBUTION AT ALL IN NORTH CAROLINA TO A 50% SHARE FOR ONE PROGRAM IN NEW YORK STATE.

IN SOME STATES, THE SERVICES ARE AVAILABLE ONLY TO LOWER INCOME FAMILIES. IN ALL STATES THAT WE CONTACTED, THERE ARE LIMITS ON OVER-ALL PAYMENTS. IN ALL CASES THERE IS STRONG POLITICAL SUPPORT TO KEEP THE LIST OF APPROVED PROCEDURES APACE WITH DEVELOPMENTS IN MEDICAL TREATMENT AND TECHNOLOGY.

IN MONTANA, $850 THOUSAND OF THE MATERNAL AND CHILD HEALTH BLOCK GRANT GOES TO SUCH A PROGRAM PROVIDING EVALUATION AND TREATMENT FOR ALL CHILDREN UP TO THE AGE OF 18 IN FAMILIES WITH INCOMES UP TO 185% OF THE POVERTY LEVEL. THE HANDICAPPED PROGRAM REPRESENTS CONSIDERABLE ASSURANCE TO LOW INCOME FAMILIES ALTHOUGH THERE IS A LIMIT OF $15,000 THAT CAN BE SPENT ON ANY CHILD. FURTHERMORE, IN THIS CASE THE STATE DOES NOT HAVE A TERTIARY CARE CENTER SO IN THE CASE OF EMERGENCY CARE OR SEVERE CONDITIONS, CONSIDERABLE FUNDS MUST BE SPENT TO TRANSPORT THE CHILD TO AN APPROPRIATE SETTING -- USUALLY AS FAR AWAY AS SALT LAKE CITY OR SEATTLE.

CALIFORNIA COUNTIES PARTICIPATE ON A 25-75% BASIS WITH THE STATE IN THE CALIFORNIA CHILDREN'S SERVICES PROGRAM. THE PURPOSE IS TO PROTECT FAMILIES FROM THE CATASTROPHIC COSTS ASSOCIATED WITH CHILDREN'S HEALTH CARE COSTS. SOME 7-9% OF THE FEDERAL MATERNAL AND CHILD HEALTH BLOCK GRANT ALSO GOES TO SUPPORT THIS $70 MILLION PROGRAM. ELIGIBILITY IS VERY GENEROUS AND FAMILIES WITH ANNUAL INCOMES UP TO $40,000 ARE COVERED ALTHOUGH PAY BACK SCHEDULES RELATED TO FAMILY INCOME ARE USED. ALTHOUGH COUNTIES SHARE IN THE COSTS OF THE PROGRAM, THE DECISION MAKING CRITERIA USED BY COUNTY HEALTH OFFICERS ARE ADOPTED AT THE STATE LEVEL.

NO COUNTY OFFICIAL DISPUTES THE NEED AND VALUE OF SUCH A PROGRAM. ALL FEAR FOR ITS COST. NEARLY ALL NEW PROCEDURES BECOME ELIGIBLE. COUNTIES CONTRIBUTED $17.8 MILLION IN 1987 TO THIS PROGRAM.

ONE POINT OF INTEREST ABOUT THIS PROGRAM IS WHAT HAPPENS WHEN THE FUND RUNS OUT OF MONEY. IN MONTEREY COUNTY ALONE, THERE ARE 2,000 ELIGIBLE CHILDREN. IN GENERAL THE PROGRAM IS AVAILABLE ON A FIRST COME FIRST SERVE BASIS. THIS PAST YEAR, ONE CASE FOR BONE MARROW TRANSPLANT AND ONE FOR INTENSIVE NEONATAL CARE, TOGETHER ACCOUNTED FOR OVER $500,000. WHEN MONEY RUNS OUT, THEORETICALLY, MORE MONEY CAN BE APPROPRIATED. IN REALITY, WHEN THE MONEY IS GONE THE PROTECTION IS GONE.

THIS ISSUE IS AN EXTREMELY DIFFICULT ONE. WE LOOK FORWARD TO PARTICIPATING IN DISCUSSIONS ON IT AS THIS SUBCOMMITTEE CONTINUES ITS DELIBERATIONS. WE ANTICIPATE CHILDREN'S HEALTH WILL BE INCLUDED AS PART OF SENATOR BENTSEN'S AGENDA FOR THE YEAR OF THE CHILD NEXT YEAR AND WE LOOK FORWARD TO PLAYING AN ACTIVE ROLE IN THESE ACTIVITIES.

THANK YOU AND I WOULD BE HAPPY TO ANSWER ANY QUESTIONS YOU MAY HAVE.

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* NACo IS THE ONLY NATIONAL ORGANIZATION REPRESENTING COUNTY GOVERNMENT IN THE UNITED STATES. THROUGH ITS MEMBERSHIP, URBAN, SUBURBAN, AND RURAL COUNTIES JOIN TOGETHER TO BUILD EFFECTIVE, RESPONSIVE COUNTY GOVERNMENT. THE GOALS OF THE ORGANIZATION ARE TO: IMPROVE COUNTY GOVERNMENT; SERVE AS THE NATIONAL SPOKESMAN FOR COUNTY GOVERNMENT; ACT AS A LIAISON BETWEEN THE NATION'S COUNTIES AND OTHER LEVELS OF GOVERNMENT; AND ACHIEVE PUBLIC UNDERSTANDING OF THE ROLE OF COUNTIES IN THE FEDERAL SYSTEM.

American Psychiatric Association

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The American Psychiatric Association, a medical specialty society representing more than 34,000 physicians nationwide, is pleased to submit this testimony on child health programs, with particular emphasis on mental health programs. While children with mental health problems are covered by a wide range of Federally funded programs, coverage varies and access to the services may be impeded due to lack of coordination and other problems. APA's testimony focuses on estimates of the number of children with mental disorders, current available funding for children with mental disorders and options for addressing future needs.

Estimates of the Need

Estimates of the number of children under 18 years of age who have mental health problems range from 5 % to 15 % of the population. The Congressional Office of Technology Assessment's December 1986 background paper on Children's Mental Health: Problems and Services estimated that between 12 percent and 15 percent or between 7.5 million and 9.5 million of the approximately 63 million U.S. children under the age of 18 suffer from mental disorders that warrant intervention, but less than 1 percent of our children receive treatment in a hospital or residential treatment facility and approximately 5 percent or 2 million children receive outpatient mental health treatment.

In addition to children who have diagnosable mental disorders, certain environmental risk factors such as poverty, divorce, alchoholic parents, and child abuse may place children at risk and may require early intervention. Identification of children's mental health problems is much more difficult than with adults. Despite problems associated with the research on children's mental health problems and

effective treatments (limited research; not methodologically rigorous), the Congressional Office of Technology Assessment (OTA) concluded that "...treatment is better than no treatment and that there is substantial evidence for the effectiveness of many specific treatments."

Despite the numerous studies that have identified many children with mental disorders, the exact numbers within the population who need mental health services have not been adequately determined. Appropriate studies of the prevalence of these disorders still need to be conducted.

Federal Funding of Service Delivery to children with mental disorders

The major Federal programs affecting the delivery of mental health services to children include: the Alchohol, Drug Abuse and Mental Health (ADM) block grant program, third party payment programs such as Medicaid, Medicare and CHAMPUS (Civilian Health and Medical Program of the Uniformed Services); Mental Health services provided under the Education for All Handicapped Children Act (PL 94-142); and CASSP (Child Adolescent Service System) funded through the National Institute of Mental Health (NIMH).

The proportion of expenditures specifically for children's mental health needs through these programs is difficult to determine, but one study of State Mental Health Agencies (SMHAs) conducted by the National Association of State Mental Health Program Directors found in 1983 that 7% or $9 per capita was spent on childrens mental health services versus 45% or $22 per capita on adult mental health services.

Numerous Presidential Commissions and private commissions since the beginning of this century have specifically dealt with the need for new programs for mentally disturbed children including the White House Conference on Children (1909), the Joint Commission on Mental Health

of Children (1975), the Project on the Classification of Exceptional Children (1975), The Presidential Commission on Mental Health and its Task Force on Infants, Children, and Adolescents (1978), Select Panel for the Promotion of Child Health (1981), Knuitzer/Children's Defense Fund Survey of State Mental Health Programs (1981, 1982). All of these reports continue to point to the dearth of well-coordinated services provided to mentally ill children and the need for more available services for this population. Coordination of service delivery is a particular problem because of the overlay and overlapping responsibilities of the health care system, the educational system and the social welfare system.

Under the ADM block grant (PL 97-035), funds are provided to the states for provision of mental health services. The proportion of these funds specifically allocated for children is not known because the block grant is segmented with specific funds for alchohol, drug abuse, and mental health programs, and the percentage of block grant funds allocated to mental health services differs among the States. It is also unknown which of the three categories of programs has specifically allocated funds for children services. In addition, although the original Community Mental Health Centers Act of 1963 required these centers to specifically report on funds spent on children, this reporting mechanism is no longer specifically required. Since CMHCs receive the bulk of mental health funds but are not required to provide a certain level of service to children or to report on how much is spent on children (despite specific requirements for providing specialized outpatient childrens services), little can be known about actual expenditures. The 1985 ADM block grant however did require a 10 percent set aside for childrens' services. This entire set aside may however be no more than 20 million dollars nationwide--not a great deal of money to meet the extensive needs of the child population.

In 1985 Medicaid served 11 million dependent children under the age of 21, but the amount of mental health services provided to this group is

unknown. A GAO report on this issue is scheduled to be released by the end of the year. While the actual amount of mental health services provided to Medicaid eligible children is unknown, the Medicaid program provides coverage for a wide variety of mental health services. Through coverage of SSI-related children, Medicaid is a significant payer of institutional care. Mandatory Mediciad services include: inpatient hospitalization, outpatient hospital services including day treatment and other forms of partial hospitalization, physicians (including psychiatrists) services, and Early and Periodic, Screening, Diagnosis and Treatment program services (EPSDT). Optional services include: prescription drugs, case management, clinic services (including community mental health psychologists and social worker services, inpatient psychiatric facilities, intermediate care facilities for the mentally retarded and developmentally disabled (ICF/ME,DD), and other home and community-based services approved through the waiver program. An expansion of eligibility under Medicaid in 1984 did not specifically require mental health services or assessment for children, but a 1986 provision allowing case management so that children could have access to needed services may prove beneficial to mentally ill children. But low financial eligibility overall, and wide variations in eligibility criteria and the extent of coverage among the states limit the potential of Medicaid as a payer of services. Although more than half of the states offer potentially unlimited coverage of many services, some states provide as litttle as $450 per year or as few as 12 visits for outpatient services. As mentioned previously, the GAO report analyzing Medicaid provision of mental health services may shed further light on this issue.

Medicare covers some (but very few) mentally disabled children but bears special important because many states have adopted medicare rules for payment. The Education for all Handicapped Children Act (PL 94-142) provides a free appropriate education and related services to all handicapped children the Federal Government provides a small amount